

WOMEN'S HEALTH In FOCUS AT NIH

NIH National Institutes of Health

A Quarterly Publication of the NIH Office of Research on Women's Health NATIONAL INSTITUTES OF HEALTH • OFFICE OF THE DIRECTOR | VOLUME 2, ISSUE 1, 2019



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Scientists Address Maternal Mortality in the United States

Popular news media have raised public awareness of some recent troubling population health statistics. Last year, the Centers for Disease Control and Prevention (CDC) announced that the U.S. life expectancy had dropped from 78.7 years in 2016 to 78.6 years in 2017, the second such decline in three years. Raising further concerns were widely publicized news stories on an increase in pregnancy-related deaths and morbidities in the United States, notably the National Public Radio/ProPublica series "Lost Mothers," a New York Times article on the loss of obstetric services in rural communities, and the ominously named USA Today series "Deadly Deliveries."

While these news stories paint a grim picture, in some cases sensationally so, the health data tracking these trends have raised legitimate concerns among biomedical researchers and health care practitioners. Each year, about 700 women die in the United States from pregnancy- or delivery-related complications. With 26.4 maternal deaths for every 100,000 live births, the United States has the highest rates of maternal mortality in the developed world. These rates are comparable to those of Turkey and Libya and much higher than the rates of Canada, Australia, and western European nations, which range from 3.8 to 9.2 maternal deaths for every 100,000 live births. Worldwide, maternal mortality declined 44% from 1990 to 2015—48% in developed nations. Afghanistan, Sudan, and the United States are the only nations where maternal mortality is on the rise.

Most pregnancy-related deaths are preventable. Though estimates vary, most studies agree that appropriate and timely medical intervention can prevent at least half of the maternal mortalities in the United States. A recent report from CDC examining maternal deaths in nine U.S. States indicated that 63% of maternal deaths were preventable. These troubling findings have prompted NIH and the biomedical community as a whole to take action.

Improving Data Collection on Maternal Mortality

"Part of the problem of understanding maternal mortality in this country is simply a lack of accurate information," says Marian MacDorman, Ph.D., an NIH-supported researcher from the Maryland Population Research Center at the University of Maryland who studies the maternal mortality data collection process. Prior to 2003, maternal deaths were underreported in vital statistics. In 2003, a checkbox was added to the standard U.S. death certificate to determine whether a woman was pregnant or postpartum at the time of death. However, inconsistent and delayed adoption of the new checkbox among the States led to irregular data collection and data incompatibilities. Because of the resulting problems in the dataset, the National Vital Statistics System (NVSS) of CDC's National Center for Health Statistics (NCHS) has not published an official maternal mortality rate since 2007. "Mongolia and Croatia publish

Marian MacDorman, Ph.D.

maternal mortality rates," says Dr. MacDorman, "But not the United States."

Dr. MacDorman and colleagues opted to examine the States' problematic maternal mortality data and used corrective statistical methods to "disentangle" them. They found that, between 2000 and 2014, maternal mortality had increased by 26.6% in the United States, excluding Texas, which experienced a sharp increase in 2011–2012,

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DIRECTOR'S CORNER

Maternal Health

Diana Bianchi, M.D., Ph.D., M.B.A., Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), asserts that pregnancy serves as a "stress test" for many medical problems later in life, such as diabetes, hypertension, and cardiovascular disease. Even in the absence of these major health concerns, the dynamic physiologic state of pregnancy profoundly affects a woman's health, not only through gestation and the postpartum period, but across the remainder of her life course.

We devote this issue of Women's Health in Focus at NIH to maternal health, including associated health risks and benefits that may manifest years—even decades—after pregnancy. For instance, gestational diabetes mellitus increases the risk of diabetes after pregnancy. Although women who have never been pregnant have an increased risk of breast cancer, some studies suggest that pregnancy both increases and decreases the risk of breast cancer at different stages of a woman's life (see "Protective Effects..." on p. 20). Further, preeclampsia predicts laterlife hypertension.

and California, which showed a decline. ¹¹ The United States stood in stark contrast to international maternal mortality trends, which had declined over the same period.

However, more recent studies by Dr. MacDorman and others have identified overreporting of maternal deaths with the checkbox (i.e., checking this box on the death certificate when the deceased woman was neither pregnant nor postpartum), which has inflated maternal mortality rates by as much as 50%. ¹³⁻¹⁶ "There's more overreporting of maternal deaths for women of advanced maternal age and women who died of ill-defined causes," Dr. MacDorman says, which further complicates attempts to obtain accurate data.

Other factors also complicate the collection of maternal mortality data. In addition to vital statistics, two other data systems—both of which draw information from vital statistics data—provide information on maternal mortality. The Pregnancy Mortality Surveillance System uses slightly different measures, distinguishing between "pregnancy-related" and "pregnancy-associated" deaths, and it defines maternal deaths as occurring during pregnancy or up to 1 year following birth.⁶ In contrast, the NVSS uses the World Health Organization (WHO) definition, restricting maternal deaths to pregnancy and up to 6 weeks postpartum. WHO also defines "late maternal deaths," which occur 6 weeks to 1 year following birth.^{17,18} "I'm not that concerned about the differing definitions," says Dr. MacDorman. "If we include WHO's late maternal deaths, they are not that different, and the important thing is to get accurate information on maternal mortality, regardless of which definitions are used." State maternal mortality review committees also provide more detailed information on maternal deaths than the vital statistics system and may use slightly different definitions, depending on the goals of their studies.

Dr. MacDorman makes several practical recommendations for increasing the accuracy of data collection on maternal mortality, a necessary step in mitigating this national public health concern. Medical certifiers should receive thorough training, understand what constitutes a pregnancy-related death, and use greater scrutiny in completing death certificates. NCHS should evaluate and standardize its coding process; query States and medical certifiers in all cases of maternal mortality, especially those most likely to be in error; and confirm pregnancy status by crosschecking other medical records. Local, State, and Federal statisticians should review annual maternal mortality data each year and take steps to ensure accuracy. Dr. MacDorman says, "As of 2017, all U.S. States except California use the NCHS method for maternal mortality data collection. California asks about pregnancies within the past year. We now have the resources and infrastructure to collect accurate data."

Reducing Racial and Ethnic Maternal Mortality Disparities

Racial and ethnic disparities in maternal mortality rates point to substantial health inequalities in the United States. Black women are three to four times more likely to die from pregnancy-related causes than White women, although the leading causes of death are similar for both races. 19-23 More than twice as many African-American mothers receive no prenatal care or prenatal care only late in their pregnancies as White mothers. 24,25 Although maternal mortality is on the rise for all demographic groups, Black women have experienced the fastest rate of increase, up to 12 times higher than White women in some U.S. cities. 20,22 Maternal mortality rates are also elevated among Native Americans, Alaska Natives, and some Asian and Hispanic subgroups in certain regions of the United States. 21,22 Black women have the highest rates of 22 of the 25 indicators of severe maternal morbidity established by CDC²², and more than twice the risk of severe maternal morbidity than White women. 21,26 While racial and ethnic disparities exist across a wide range of health conditions, 23 the inequalities uniquely related to maternal mortality warrant expert attention.

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Our feature story describes a deeply troubling health trend: the increase in maternal deaths in the United States, at least half of which are preventable. Ours is one of a handful nations where maternal mortality is on the rise, and our peer nations experience substantially lower maternal death rates. In the United States, Black women are three to four times more likely than White women to die of pregnancy-related causes. The underpinnings of this alarming disparity are manifold and suggest grave racial and ethnic inequities.

This issue of Women's Health in Focus at NIH describes some of the causes, investigations, and treatments of these and other maternal health concerns, as well as other news and events relevant to ORWH's mission. We also set the stage for this year's NIH Vivian W. Pinn Symposium, "Improving Maternal Health: Behind the Numbers," which ORWH will host on May 15 on the NIH main campus.



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Elizabeth A. Howell, M.D., M.P.P.

NIH-funded researcher Elizabeth A. Howell, M.D., M.P.P., of the Icahn School of Medicine at Mount Sinai, studies the racial and ethnic disparities in obstetrics, and much of her research focuses on how the quality of hospital and delivery care contributes to pregnancy outcomes. Dr. Howell's research team conducted a series of studies of hospitals in New York City. Analyzing population-based data, the investigators found that Black and Hispanic women were more likely than White women to deliver in hospitals with higher rates of severe maternal morbidity.^{22,26,27} "We found that risk of severe maternal morbidity could be six to seven times higher at one hospital compared with others,"

Dr. Howell says. "In our model, almost half of the Black-White disparity—and almost a third of the Hispanic-White disparity—can be explained by delivery hospital." Nationwide, racial and ethnic trends in maternal morbidity and mortality as they relate to site of delivery are similar to those in New York City.²⁸

However, in another study, Dr. Howell's team found that improving some parameters of obstetric quality neither reduced the rates of maternal mortality nor narrowed racial and ethnic disparities in pregnancy outcomes. For instance, improvements in obstetric quality and safety indicators established by the Agency for Healthcare Research and Quality (AHRQ) did not result in reductions in maternal mortality. Dr. Howell explains, "The AHRQ measures have been validated and serve a useful purpose, but they are ascertained through administrative data generated by diagnosis and procedure codes and may not be associated with the underlying factors that are most important for explaining variation between hospitals in maternal mortality. If the indicators were linked more directly to the preventable causes of maternal mortality—such as standardized hemorrhage protocols in the labor and delivery unit—we might gain more insight into how hospital quality relates to pregnancy outcomes."

Dr. Howell suggests several ways to narrow these obstetric racial and ethnic disparities. Currently, she and her colleagues are conducting a qualitative study interviewing patients and hospital staff members to try to gain insight regarding the varying risk of severe maternal morbidity among hospitals and to identify why minority women tend to deliver at hospitals with higher rates of maternal morbidity and mortality. She recommends that hospitals take the following steps to address these disparities. One, obstetric units should standardize care with the safety "bundles" established by the Alliance for Innovation on Maternal Health (AIM). These bundles are sets of evidence-driven best practices for maternity care and include protocols for medical issues common to delivery, such as hemorrhage, venous thromboembolic disease, and hypertension.²⁰ Two, clinicians and hospital staff should receive training on shared decision-making, cultural competency, and implicit bias.²⁰ Three, hospitals should implement a "disparities dashboard," a reporting platform that stratifies quality metrics by race and ethnicity, allowing hospitals and health care systems to identify disparities and monitor performance on quality metrics for groups with higher risks of poor outcomes.²⁰ Dr. Howell also recommends that Maternal Mortality Review Committees (MMRCs) review instances of maternal morbidity and mortality through the lens of race and ethnicity to determine when and how disparities contribute to cause of death.

The Preventing Maternal Deaths Act of 2018 and MMRCs

In December 2018, the Preventing Maternal Deaths Act was signed into law²⁹ and received praise from leading medical societies concerned with maternal health, such as the

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American College of Obstetricians and Gynecologists (ACOG)³⁰ and the Preeclampsia Foundation.³¹ The new law provides Federal funds for States to establish and run MMRCs. These committees comprise multidisciplinary experts in policy and maternal, infant, and public health who investigate individual cases of maternal mortality, develop prevention recommendations, and help implement them.⁵ Currently, 35 States and many cities have MMRCs,⁵ and the new law will help others establish them as well. The Preventing Maternal Deaths Act will also help to standardize the collection, archiving, and analysis of national maternal mortality data and solve many data collection problems. CDC's program Review to Action will also help local MMRCs by providing a library of information and other resources.³²

Judging from the success of MMRCs in the United Kingdom, California, and other U.S. States, many medical and policy experts agree that MMRCs can be a powerful force for change. "We learn the most when we study in-depth the medical records of actual deaths in maternal mortality reviews," says Dr. Howell. "In these reviews, we often identify how an adverse outcome could be prevented in the future by avoiding failures of communication, delayed diagnoses, and other things that can make the difference between morbidity and death."

California Realizes Declining Maternal Mortality

CMQCC
California Maternal
Quality Care Collaborative

In response to increasing instances of maternal mortality in the early 2000s, the State of California established its own MMRC in 2006 as part of the California Maternal Quality Care Collaborative (CMQCC), a public-private

partnership for improving maternal health and reducing maternal deaths. ^{33,34} California's maternal mortality rate declined more than 55% from 2006 to 2013, at a time when rates were climbing in the rest of the country. Between 2014 and 2016, maternal morbidity declined by 20.8% in 126 California hospitals participating in collaborative projects to reduce maternal hemorrhage and preeclampsia. ³⁵ Further, CMQCC maintains a maternal health data system to support quality improvement, provides quality improvement toolkits for health care providers to enhance care and reduce adverse pregnancy outcomes, and engages in outreach efforts to improve outcomes for mothers and their babies. ³⁵

Dr. Howell offers qualified praise of CMQCC: "California is a wonderful model, and they've had dramatic declines in maternal mortality for all races and ethnicities, but they acknowledge that they have not narrowed the racial and ethnic disparities in maternal morbidity and mortality."

Following in California's Footsteps: AIM and the National Network of Perinatal Quality Collaboratives

Inspired by CMQCC's success, in 2015, the Maternal and Child Health Bureau of the Health Resources and Services Administration launched AlM in collaboration with ACOG and 30 other women's health care organizations. This collaboration developed the "bundles" mentioned above, sets of protocols and best practices that have been endorsed by several national multidisciplinary organizations. He bundles resemble CMQCC's quality improvement toolkits and are designed to help health systems, hospitals, obstetric teams, and clinicians enhance the quality and safety of maternity care in four areas, known as the "4Rs": (1) readiness, (2) recognition, (3) response, and (4) review/reporting. Each bundle details 10–13 best practices and directly targets preventable causes of maternal death. Dr. Howell helped to develop a bundle that targets the "Reduction of Peripartum Racial and Ethnic Disparities." 21,22

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In 2017, CDC followed California's model in establishing the National Network of Perinatal Quality Collaboratives (NNPQC), which supports multiple local perinatal quality collaboratives. NNPQC identifies and disseminates best practices to establish, organize, and sustain perinatal quality collaboratives like CMQCC.

Improving the Health of Women and the Continuum of Care to Reduce Maternal Mortality

Much of the scientific literature as well as the experts quoted here agree that perhaps the best way to address maternal mortality is to improve the health of women and the quality of their health care across the life course—not only from preconception through the postpartum period but long before and long after as well. ^{21,22,25,37,39} Reducing the incidence and improving the treatment of common chronic conditions, such as obesity, hypertension, diabetes, and heart disease—conditions that affect women of color disproportionately—will reduce pregnancy risks, maternal mortality, and health complications that may arise long after pregnancy. ^{39,40}

Research in many medical disciplines underscores the benefits of collaborative, holistic approaches to medical care, and evidence suggests that obstetric services benefit from a similar approach. Studies have demonstrated the advantages of enhancing collaboration between obstetricians and primary care providers. Also, hospital obstetric teams can implement multidisciplinary staff meetings to assess each maternity patient's risk factors, collaboratively develop an individualized

care and delivery plan, share safety concerns with the patient and her family, and adjust the care plan according to patient feedback. Shared decision-making between the patient and the obstetrical team also affords hospital staff the opportunity to address any institutional biases.

Last year, an ACOG task force suggested considering the postpartum period the "fourth trimester," a period that is part of the continuum of pregnancy health care (see also "Don't Forget Mom's Fourth Trimester" in this issue's *In the Journals* section).⁴² Obstetric care providers can work with patients and their primary care providers to improve women's health long after pregnancy. These practices will improve the quality and safety of care from preconception to postpartum and beyond, will help reduce maternal morbidity and mortality, and will improve the health of women across the life course.

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See page 7 for descriptions of NIH programs aimed at reducing maternal morbidity and mortality. See page 23 for additional references.

SPECIAL ANNOUNCEMENT

NIH's Office of the Director (OD) Welcomes Tara Schwetz, Ph.D., as the First Associate Deputy Director

NIH Principal Deputy Director Lawrence Tabak, D.D.S., Ph.D., recently announced the appointment of Tara Schwetz, Ph.D., as NIH's first Associate Deputy Director. Dr. Schwetz oversees several OD offices, coordinates trans-OD functions, and will develop and implement a plan to enhance the efficiency and effectiveness of internal OD operations and OD interactions with ICOs. She works closely with OD leadership on administrative, scientific, technical, and infrastructure matters and supports the NIH Director in program development and evaluation as well as coordination of trans-NIH initiatives.

Dr. Schwetz joins OD from the National Institute of Allergy and Infectious Diseases (NIAID), where she served as the Chief of the Strategic Planning and Evaluation Branch in the NIAID OD and as a member of the NIAID Director's advisory team. During her tenure at NIAID, she led several efforts, including conducting an evaluation of the Centers of Excellence

for Influenza Research and Surveillance to facilitate evidence-based decisionmaking and developing the NIAID Strategic Plan for Tuberculosis Research.



Previously, Dr. Schwetz served as the Senior Advisor to the NIH Principal Deputy Director (DEPD), where she coordinated efforts such as Relmagine HHS, the NIH rigor and reproducibility activities, and the NIH-Wide Strategic Plan. Dr. Schwetz also served in the dual role of the NIH Environmental Influences on Child Health Outcomes (ECHO) Interim Associate Program Director and the Special Assistant to the DEPD. She received her Ph.D. in biophysics from the University of South Florida.

NIH Programs to Prevent Maternal Morbidity and Mortality

Multiple NIH Institutes and Centers collaborate to combat maternal morbidity and mortality and support programs, research efforts, and clinical trials to advance maternal health and prevent adverse pregnancy outcomes. Below are descriptions of a few key initiatives in this area.

ORWH's Maternal Morbidity and Mortality Resource

Page. In May, ORWH will launch a web page that will include articles, statistics, and links to NIH resources on maternal morbidity and mortality, organized by subtopic. ORWH will officially unveil the Maternal Morbidity and Mortality Resource Page at the 4th Annual NIH Vivian W. Pinn Symposium, "Improving Maternal Health: Behind the Numbers," on May 15 on the NIH Main Campus.



nuMoM2b. Since 2010, multiple clinical research sites across the United States have studied a racially, ethnically,

and geographically diverse population of over 10,000 nulliparous pregnant women (i.e., pregnant women who have never given birth and who have no history of prior delivery, labor, or pregnancy to inform care). The aim is to evaluate the causes of adverse pregnancy outcomes such as preterm birth, preeclampsia, fetal growth restriction, and stillbirth. Investigators are working to determine causal factors and predictors of these adverse outcomes, such as genetic and epigenetic biomarkers, physiological responses to pregnancy, and environmental factors. Subsidiary studies in this program include the nuMoM2b Sleep Disordered Breathing study and the nuMoM2b Heart Health Study. nuMoM2b is supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the National Heart, Lung, and Blood Institute (NHLBI), and ORWH.

LIFE-Moms. Lifestyle Interventions for Expectant Moms is a consortium of seven clinical centers testing a variety of weight management interventions involving diet, exercise, and health education for pregnant women classified as overweight or obese. LIFE-Moms investigators seek to identify effective interventions that encourage healthy gestational weight gain, help pregnant women maintain glycemic control, prevent adverse pregnancy outcomes, and reduce obesity and metabolic abnormalities in the children of the 1,150 "LIFE-Moms" thus far enrolled. LIFE-Moms is sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).



CHAP. The Chronic Hypertension and Pregnancy Project evaluates whether a blood pressure treatment strategy using

Labetalol, Nifedipine ER, or both in pregnant women with chronic hypertension can effectively and safely achieve blood pressure targets established for non-pregnant adults of reproductive age. The CHAP study will involve an estimated 4,700 pregnant women. CHAP is supported by NHLBI.

PREP. The Pravastatin to Prevent Preeclampsia in High-Risk Pregnant Women blinded placebo-controlled trial evaluates the safety and efficacy of pravastatin for women and their babies. Previous studies have suggested that this medication reverses some of the pathophysiological pathways associated with preeclampsia and that the drug has no discernable effect on fetal development. PREP will collect preliminary maternal-fetal safety data, evaluate pravastatin's pharmacokinetics, and establish dosage and response information for use in future clinical trials. PREP is supported by NICHD.

MFMU Network. The Maternal-Fetal Medicine Units Network was established in 1986 to participate in clinical trials in maternal-fetal medicine and obstetrics. The MFMU Network aims to reduce maternal, fetal, and infant morbidity and mortality related to preterm birth, fetal growth abnormalities, and maternal complications by providing the rationale for evidence-based, cost-effective obstetric practices. The MFMU Network is supported by NICHD, NHLBI, and the National Institute of Neurological Disorders and Stroke (NINDS).

Maternal Nutrition and Pre-Pregnancy Obesity: Effects on Mothers, Infants, and Children. This research grant program through the National Institute of Nursing Research (NINR) and the Office of Dietary Supplements (ODS) funds interdisciplinary research focused on maternal nutrition and pre-pregnancy obesity. Maternal obesity significantly affects the risk of complications in pregnancy and delivery, the intrauterine environment, fetal development, and the health of the mother and newborn. Studies funded through this program may evaluate the effects of pre-pregnancy obesity on maternal outcomes, explore the effects of dietary supplements on mothers and newborns, assess interventions targeting modifiable factors that modulate the genetic susceptibility to obesity, or investigate related topics.

Family Caregivers Safeguard Their Own Health and Wellness by Building Resilience

Family caregivers—the spouses, family members, and friends who provide care to those with serious health conditions—have become an intrinsic, often overlooked, part of the U.S. health care system. These caregivers perform a variety of tasks, from nursing services, such as administering medication and operating medical equipment, to daily activities involving transportation, managing finances, personal care, and household chores. Often, family caregivers manage these responsibilities alongside child care, work, and other obligations.

In the United States, 43.5 million individuals serve as family caregivers and provide 80% of the nation's long-term care. Nearly 8 million older adults with serious health issues, such as dementia, Parkinson's disease, stroke, heart disease, multiple sclerosis, and arthritis, continue to live in the community with support from family caregivers. Nost older people requiring long-term assistance rely exclusively on family and friends for care, and only 25–30% of family caregivers receive help from professional supportive health care services. 1.2

Serving as a family caregiver constitutes a significant risk factor for many physical and mental health problems, including cardiovascular disease, sleep disturbance, fatigue, pain, weight loss, chronic stress, anxiety, and depression.³⁻¹¹ The risk of emotional and psychological problems is particularly high for caregivers spending long hours caring for older adults with

advanced dementia.¹² One study found that family caregivers experienced mortality risks 63% higher than non-caregiving controls, even after adjusting for other health risk factors.¹³ Highlevel caregivers are also more likely to neglect routine self-care practices, such as exercise, rest, recuperating from illnesses, and taking prescribed medications.¹⁴

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Many family caregivers

struggle with financial hardships resulting from reduced income, loss of benefits, and stagnated careers. ^{2,10,11} Medicaid benefits provide modest stipends to some family caregivers of qualifying patients. However, this compensation is far from commensurate with their labors, as unpaid caregivers provide an estimated \$306 billion worth of services annually—almost double the cost of home health care and nursing home care combined (\$43 billion and \$115 billion, respectively).¹

Women bear a disproportionate share of the burden of family caregiving and constitute an estimated 66% of the family caregiver workforce. Female caregivers tend to spend as much as 50% more time providing care than male caregivers. Women caregivers are also more likely to have high blood pressure, diabetes, high cholesterol, heart disease, and many other health problems than male caregivers. 1.4.15.16 Overall, 65% of family care



recipients are women with a mean age of 69.4. However, a larger proportion of younger family care recipients are men (i.e., 45% of care recipients aged 18-45 are men, but only 33% aged ≥ 50 are men). 1

An estimated 5.5 million family caregivers in the United States care for veterans. While those caring for pre-9/11 veterans face situations and challenges like those of civilian caregivers, caregivers of post-9/11 veterans tend to be younger, employed, and caring for a younger family member who often has a mental health or substance use disorder.¹⁷ Like civilian caregivers, military family caregivers experience more adverse health outcomes, workrelated difficulties, and family strain than non-caregivers. Caregivers of post-9/11 veterans fare worse than caregivers of pre-9/11 veterans.¹⁷

Although family caregiving clearly takes a physical and mental toll, many caregivers have described the benefits of supporting an ailing family member, such as a sense of fulfillment, feeling closer to the patient, and knowing that their loved one is receiving adequate care. 12,18 Caregivers can mitigate their health risks with routine self-care practices, including regular exercise; sleep hygiene; proper nutrition; refraining from tobacco, illicit drugs, and excessive alcohol or caffeine; managing stress through meditation, yoga, exercise, and mindfulness techniques; receiving regular medical care; taking prescribed medications as directed; and connecting to social networks, spiritual or religious communities, and support groups online or in person. 19-24

Many family caregivers report feeling overwhelmed, hopeless, and out of control, but recent studies have shown that some caregivers can avoid these feelings by taking steps to establish a sense of self-efficacy or resilience.^{4,25-27} Acknowledging that there is no single path toward enhancing resilience in

Caregivers

The following organizations provide information and other resources to family caregivers. Visit the websites of the organizations listed below for more information.

- Family Caregivers in Cancer (National Cancer Institute)
- Family Caregivers (National Institute on Aging)
- National Institute of Nursing Research
- VA Caregiver Support (Department of Veterans Affairs)
- Family Caregiver Alliance

caring for an ailing family member, researchers advise caregivers to determine individualized steps to adapt to perceived adversity. Such steps might include the self-care practices described above, leveraging kinship ties and social supports, establishing unity and cooperation within the family, employing services such as part-time home nursing care, maintaining an "external life" outside of the care environment, and practicing healthy coping strategies.⁴

With the number of Americans over the age of 65 projected to double by 2060,²⁸ the increasing need for family caregivers warrants a sustained effort to help maintain their health, quality of life, and productivity.

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Local Review Committees Help Prevent Maternal Mortality

(Original article by <u>Zaharatos et al. 2018. J. Women's Health 27: 1-5.</u>)

Investigators from the Centers for Disease Control and Prevention (CDC) recently reported on efforts to support Maternal Mortality Review Committees (MMRCs), local review boards that analyze government, medical, and social data to understand the causes of maternal mortality, a growing problem in the United States.

Domestically, from the early 1990s to 2013, the number of deaths from pregnancy-related causes increased from approximately 10 deaths out of every 100,000 live births to 17. Black women are three to four times more likely to experience maternal death than White women, and the mortality data suggest other troubling racial and geographic disparities. Half of pregnancy-related deaths are preventable and often result from several intersectional factors, suggesting the need for collaborative interventions from multisector stakeholders.

Thus, CDC and other organizations established the "Building U.S. Capacity to Review and Prevent Maternal Deaths" initiative in 2015 to consult with local MMRCs to identify effective practices for reducing maternal mortality. The initiative team established a model of a "fully functional" MMRC: one that collects and uses accurate data to inform policy and practice, one that runs prevention programs to improve care, and one that demonstrates reductions in maternal death. For instance, one Ohiobased MMRC identified and responded to a community need by organizing training simulations to prepare hospitals to treat hemorrhage and other obstetric emergencies. The initiative team also maintains a data system, creates tools for assessing individual cases of maternal death, and supports the establishment of new committees to add to the increasing

number of MMRCs. More information is available at www.reviewtoaction.org/.

Higher Incidence of Risk Factors Fails to Explain Increasing Trend of Maternal Morbidity

(Original article by Leonard et al. 2019. BMC Pregnancy Childbirth 19: 16.)

Over the past 15 years, instances of life-threatening maternal morbidity have more than doubled in the United States. Severe maternal morbidity affects more than 50,000 women each year, approximately 1.4% of all deliveries. A recent study found that, although advanced maternal age, pre-pregnancy comorbidities, and cesarean delivery contribute to severe maternal morbidity, these risk factors do not seem to be driving the increasing trend of lifethreatening childbirth complications.

Stephanie A. Leonard, Ph.D., Stanford University School of Medicine, and colleagues conducted a population-based study of the over 3.5 million live births in California from 2007 to 2014. The investigators analyzed data from patient discharge and birth records, indexing risk factors with 18 diagnosis and procedure indicators of maternal morbidity (e.g., blood transfusion, respiratory distress, renal failure) identified by the Centers for Disease Control and Prevention (CDC).

Advanced maternal age (≥35 years) and pre-pregnancy comorbidity (e.g., hypertension, chronic renal disease, congenital heart disease) were associated with severe maternal morbidity. However, pre-pregnancy obesity (body mass index ≥30) was not. In women with severe maternal morbidity, cesarean delivery and pre-pregnancy comorbidities were twice as common, and cesarean delivery was associated with 2.7 times the risk of severe maternal morbidity. The prevalence of severe maternal morbidity increased 65% during the study period, and the prevalence of three of the risk factors associated with severe maternal morbidity—advanced

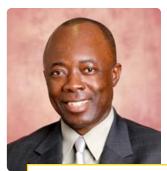
maternal age, obesity, and comorbidity—also increased in the same time frame.
Cesarean deliveries remained consistent.
Contrary to expectations, the increases in three of the risk factors studied did not explain the dramatic increases in the trend of severe maternal mortality.

With these unexpected results, Dr. Leonard and colleagues emphasize the need for further study to identify the potential causes of current maternal morbidity trends. The researchers speculate that changing patterns of access to health care may represent a possible factor underlying the increase in severe maternal morbidity.

Poor Sleep May Increase Risk for Gestational Diabetes in Non-Hispanic Blacks

(Original Article by <u>Chirwa et al. 2018. Int. J. Environ. Res. Public Health 15: 2287.</u>)

Sleep deprivation or lack of high-quality sleep is a common concern during pregnancy. However, few studies examine poor sleep as a risk factor for poor pregnancy outcomes, especially in non-Hispanic Blacks, who are three times more likely than Whites to die during pregnancy in the United States. Sanika Chirwa, Ph.D., and colleagues at Meharry Medical College explored this issue in a pilot study supported by the National Institute on Minority Health and Health Disparities (NIMHD) and the National Center for Advancing Translational Sciences (NCATS). This study focused on monitoring sleep and diabetes in 60 otherwise healthy non-Hispanic Black women ages 18-35, who were visiting the clinic for regular wellwoman exams or pregnancy follow-ups. Study measures included the women's socioeconomic and health status, how far along their pregnancies were if they were pregnant, and responses to two questionnaires: one on quality of sleep and the other on depression status. Study participants received wrist-mounted



Sanika Chirwa, Ph.D.

devices to monitor their daily sleep time for one week. The women returned to the clinic to get lab tests to check their blood sugar (HbA1c) levels and other lab values. Results showed that worse sleep was associated with higher HbA1c levels in both pregnant and non-pregnant women. Also, poor sleepers reported more signs of depression. Such findings support the hypothesis that poor sleep quality may increase a pregnant woman's risk of developing gestational diabetes and associated health complications. The authors recommended that clinicians evaluate pregnant mothers' sleep and HbA1c each trimester and offer advice to improve the well-being of both mother and child.

Pregnancy Represents a Critical Time for Later Diabetes

(Original article by <u>Lowe et al. 2018</u>. <u>JAMA</u> 320: 1005-1016.)

A woman's health during her pregnancy is a critical determinant of her health in later life. As NIH recently announced, mothers with elevated blood glucose, even those who do not meet the traditional threshold for gestational diabetes, are significantly more likely to develop type 2 diabetes after pregnancy than mothers without elevated blood glucose. The Hyperglycemia and Adverse Pregnancy Outcomes Follow-up Study (HAPO FUS) followed mothers and their children for 10-14 years after birth. The National Institute of Diabetes and Digestive and Kidney Diseases provided funds for this study. HAPO FUS findings

challenge the standard Carpenter-Coustan criteria of gestational diabetes and suggest that the more stringent International Association of Diabetes and Pregnancy Study Groups criteria are more predictive of type 2 diabetes. William L. Lowe, Jr., M.D., and his fellow study authors recommend closer examination of blood glucose during pregnancy and call for effective pregnancy interventions in cases of elevated blood glucose to improve the future health of both mothers and their babies.

Loss of Obstetric Services in Rural Counties Affects Birth Outcomes

(Original article by <u>Kozhimannil et al. 2018.</u> JAMA 319: 1239-1247.)

Women in rural areas of the United States have long had less access to obstetric services than their urban counterparts, and the availability of these essential services is decreasing. Only 55% of rural U.S. counties had obstetric units in 2004, and this percentage had decreased to 46% by 2014. This trend may compound existing neonatal and maternal health problems common in rural areas, such as low birth weight, pregnancy-related hospitalizations, and higher rates of infant mortality than in urban areas. The loss of rural obstetric units also correlates with significant changes in birth outcomes. In the year after the loss of services, expectant mothers in rural counties not adjacent to urban areas had more out-of-hospital and preterm (<37 weeks gestation) births and used less prenatal care compared with rural counties with continued obstetric capacity. Additionally, in the years following the loss of obstetric services, rural counties—both close to and distant from urban areas—saw an increase in the number of births in hospitals without obstetric units. These findings resulted from statistical analysis of data from the National Center for Health Statistics and the American Hospital Association

Annual Survey pertaining to the almost 5 million births from 2004 to 2014 in 1,086 rural U.S. counties, 179 of which had lost obstetric services.

The implications of these findings may shape future rural maternal health care. For instance, without obstetric units, responsibility for prenatal care, labor, and delivery will shift to local clinics, which may be under-equipped and lack trained staff members to provide quality care. Further, complications with at-home births or deliveries outside of obstetric units will increase the workload of nearby hospitals and emergency services. Such considerations will affect health care management in rural areas and may give rise to obstetric models involving regionalization strategies, partnerships with larger health care systems, and telehealth services.

Don't Forget Mom's Fourth Trimester

(Original article by <u>Verbiest et al. 2018.</u> J. Behav. Med. 41: 577-590.)

The Patient-Centered Outcomes Research Institute (PCORI) encourages health care providers to consider the "fourth trimester," the first 12 weeks postpartum when mothers experience biological, emotional, and social changes, as an important part of the continuum of pregnancy care. PCORI's 4th Trimester Project worked with new mothers, health care providers, and advocates to identify unmet needs before delivery and immediately postpartum and to develop priorities for improving postpartum care. A racially diverse group of 22 mothers participated in the project from February 2016 to August 2017 through a series of monthly in-person or virtual meetings.

Investigators found that postpartum mothers want to share their experiences and process the postpartum experience. Mothers are highly attuned to provider health messaging but often leave the office without clear direction on next

steps. Postpartum groups can address both emotional and resource-oriented needs and can form a strong arm of a new mother's support system. Providers and new mothers generally agreed that more research could help to define a gamut of "normal" postpartum experiences ranging from sleep hygiene with infants to breastfeeding challenges, body image, anxiety and depression in concert with hormonal fluctuations, and much more.

Although some of the complex issues raised by study mothers cannot be easily addressed, many practical, actionable recommendations emerged from the project. These suggestions included encouraging care providers to inform pregnant women what to expect during the postpartum period; to discuss topics such as incontinence, intimate relationships, exhaustion, and anxiety in a supportive way; to remind pregnant women that their infants and other young children are welcome at postpartum visits; to offer walk-in postpartum visits; and to ensure more

integrated care by facilitating meetings with lactation consultants and mental health care providers. The researchers also emphasize the special postpartum challenges of marginalized women for whom institutionalized racism and poverty may further complicate the fourth trimester.

The postpartum period is a crucial time in which mothers and families adjust to new roles and realities. As such, the fourth trimester represents an important stage of pregnancy-related care that warrants greater attention by the research and clinical communities.

Early Screening Identifies Risks and Can Help Prevent Maternal Diabetes

(Original article by <u>Hinkle et al. 2018.</u> Sci. Rep. 8: 12249.)

First-trimester glycated hemoglobin (HbA1c) tests of over 2,000 pregnant women with low-risk pregnancies

predicted gestational diabetes mellitus (GDM) in a case-control investigation within the prospective NICHD Fetal **Growth Studies-Singleton Cohort** (2009-2013) study. Stefanie N. Hinkle, Ph.D., and colleagues showed that an increase in hyperglycemia is associated with GDM risk in a positive, linear direction. Pregnant women who later developed GDM tended to have significantly higher HbA1c levels in their first trimester than women who did not develop GDM. The investigators determined that each 0.1% increase in HbA1c at 8-13 weeks increased the risk of developing GDM by 22%. NIH recently announced that the implications of early detection are broad and indicate early interventions, such as diet changes and regular exercise targeted at those with highest risk. Additionally, the study authors suggest the potential that hyperglycemia in non-diabetic women can be assessed and addressed prior to pregnancy to promote the health of mother and baby.

WOMEN IN SCIENCE

Featured Research and Perspectives

Qualitative Study Identifies Common Challenges of Hospital Physicians During and After Pregnancy

(Original article by Gottenborg et al. 2018. J. Hosp. Med. 13: 836-839.)

A recent study finds that new and expecting mothers serving as hospital physicians typically face a common set of challenges that can affect their professional development and overall wellness. These challenges include difficulties with accessing parental leave, the physical demands of the job, loss of professional opportunities, and negative responses from colleagues. Researchers conducted interviews with 10 female academic hospitalists from across the United States about their experiences working while pregnant, taking parental leave, and returning to work. The investigators then coded and

analyzed transcriptions of the interviews with a qualitative data analysis software program to identify shared experiences. Most of the women interviewed described difficulties with taking leave, including a lack of transparency in family leave policies, negotiating time off with supervisors and human resources, and the financial burden of unpaid leave. All participants described the physical difficulty of coping with fatigue when pregnant and after returning to work while caring for an infant. A majority of the physicians identified finding time and adequate facilities to pump breastmilk as a particular challenge. Some of the women reported missing out on professional opportunities and negative responses from colleagues, while others reported a more accommodating and supportive response from coworkers. Finally, all participants claimed that their new roles as mothers increased their empathy for their patients. The researchers suggest that their findings could inform institutional changes to improve the workplace productivity of hospitalists who are new or expecting mothers and better accommodate their needs.

Inconsistent Family Leave Policies May Hinder Life-Work Balance for Medical Residents

(Original article by Magudia et al. 2018. JAMA 320: 2372-2374.)

A recent "research letter" to the Journal of the American Medical Association reports wide variation in the leave policies for childbearing mothers and family (non-birth mothers, fathers, and adoptive parents) working as medical residents in 15 teaching hospitals affiliated with 12 of the nation's top medical schools. Only 8 of the 15 teaching hospitals studied had established childbearing or family leave policies for medical residents. These policies afforded a mean paid leave period of 6.6 weeks (range of 2–10 weeks) for childbearing mothers and 3.9 weeks (range of 1–8 weeks) for adoptive and non-birth

parents. The remaining teaching hospitals had no established childbearing or family leave policies for medical residents other than allowing use of sick leave, vacation time, and disability benefits. In contrast, similar policies at the nation's top 12 medical schools offered an average of 8.6 weeks of paid leave for faculty physicians. The researchers express concern that the inconsistent policies and limited family leave benefits constitute an unfair burden on new physicians, who often are completing their medical residencies during prime childbearing years. The investigators posit that current family leave policies for medical residents remain inconsistent with balancing career and family; with accommodating the physical and emotional needs of new parents and infants, including parent-child bonding; with advancing professional equity for women and men in the medical field; and with promoting human health.

SCIENTIST SPOTLIGHT

Dr. Judith A. Salerno is a board-certified physician and the President of the New York Academy of Medicine, an organization prioritizing research, policies, and programs that take an evidence-based approach toward examining and overcoming the barriers to good health and health equity. Dr. Salerno is also a member of the National Academy of Medicine (NAM) Roundtable on Quality Care for People with Serious Illness, a Commissioner of the Lancet Commission on Global Access to Palliative Care and Pain Relief, and a member of the Advisory Board of the University of Southern California's Schaeffer Center for Health Policy and Economics.

In 2018, Dr. Salerno was elected to the prestigious NAM, where she had previously served as the Leonard D. Schaeffer Executive Officer from 2008 to 2013, when NAM was known as the Institute of Medicine (IOM). Dr. Salerno led the collaboration between IOM and HBO to produce *The Weight of the Nation*, a 2012 Emmy-nominated documentary series on the problem of obesity in the United States, and co-authored an accompanying book analyzing causes and possible solutions to the epidemic.

Dr. Salerno also served as the President and Chief Executive of Susan G. Komen,

the nation's largest breast cancer research and advocacy organization, where she oversaw operations, guided the development of a new strategic direction, and directed the launch of an innovative \$27 million, 10-city health equity initiative.

Earlier in her career, Dr. Salerno was the Deputy Director of NIH's National Institute on Aging (NIA), where she helped advance research on hypertension, on neurodegenerative diseases such as Alzheimer's, and on the behavioral, social, demographic, and stigmatizing aspects of aging. She was also a Chief Consultant for Geriatrics and Extended Care for the U.S. Veterans Health Administration and a co-founder of the Washington, DC, Area Geriatric Education Center Consortium.

Dr. Salerno earned her medical degree from Harvard Medical School and her Master of Science from the Harvard School of Public Health.

What have been the most rewarding aspects of your career?

Reflecting on an immensely rewarding career, I find deep satisfaction in knowing that I have remained committed to ensuring that everyone has opportunity to live a healthy life. Health equity



has been the unifying theme of my professional life, whether working to improve care for veterans, those living with metastatic breast cancer, Medicaid recipients, or Alzheimer's patients. As President of the New York Academy of Medicine, I am gratified to have the opportunity to shape the future of an organization that was founded 172 years ago on these principles and to galvanize people around issues of health equity.

What are the barriers to women in science?

Science has become more welcoming for women since my days in the intramural lab at NIH, when I was a single mom



with three young kids, struggling to do it all on two or three hours of sleep a night. Unfortunately, barriers to the advancement of women in science remain. They are perhaps subtler than they were in the 1990s yet still challenging. There is still a dearth of women in leadership positions in the scientific community, and persistent inequities in salaries between men and women remain, to name but a few. I often speak with young women in science and medicine who are trying to find a healthy balance between their personal and professional lives and wrestle with feelings of inadequacy. I tell them that the systems and our culture are inadequate, not them. Academic and research institutions can and should do more to ensure the next generation of female scientists have the support they need to achieve to their potential.

Do you have advice for young female scientists?

Seek out women you admire as mentors. Observe them, engage them, use them as sounding boards, and keep the bond strong. Finding a great mentor is more important than finding role models to look up to. A great mentorship relationship can also strengthen your self-confidence, help banish self-doubt, and affirm your abilities and contributions. Not just a single mentor—build yourself a network of strong women mentors and peers who

will encourage and support you. I was fortunate that, early in my career, the late Ruth Kirschstein, M.D., the first woman appointed director of an NIH Institute, took me under her wing. She provided me with valuable insights and support, especially after I returned to NIH in a senior leadership position. I felt that I was the beneficiary (one of many) of her wisdom and experience.

Has the trajectory of your career changed over time?

I have had a wonderfully rich set of experiences over the course of my career. Every seven years or so, my path has taken a turn that has led to unexpected and exciting new opportunities and challenges, leading up to my current position as President at the New York Academy of Medicine. At face value, each position I've held seems quite differentfrom working in a lab, to leading a nationwide veterans' program, to running a major health policy organization and a large cancer nonprofit—but my focus on connecting people to resources that enable them to live their healthiest lives has never wavered. I'm excited about what's in store for the next seven years!

Why is it important to support and encourage the next generation of female scientists?

While it is particularly important to encourage and support all scientists during this time of significant change to

health care policy and funding, leveling the playing field for women is at a critical juncture. Much more needs to be done: elevating women to leadership positions, reducing pay disparities, and preventing gender discrimination. I have recently committed to an advisory board position at the newly established organization TIME'S UP Healthcare to ensure that women in these fields are not left behind in the national movement to ensure equity, safety, and dignity for women in the workplace.

Who were your scientific role models?

I have a deep admiration for women pioneers in science and medicine. My earliest memory of being energized about science goes back to my childhood when I read a biography of Elizabeth Blackwell, M.D., the first woman to receive a medical degree in the United States. Of course, the story of Rosalind Franklin, Ph.D., who captured the first X-ray diffraction images of DNA, leading to the discovery of the double helix, should be told and retold. If not for the advances. stature, and inspiration of women I met like Dr. Kirschstein. I might never have been able to imagine the career I've been privileged to have.

What other female scientists do you admire and why?

Today, I most admire the women who are doing great science while also addressing tough societal and cultural issues. Take Mary-Claire King, Ph.D., for example. Not only are her scientific breakthroughs revolutionary—including the discovery of the BRCA1 cancer risk gene—but her work that applied scientific knowledge to human rights causes, such as using genetics to identify remains of individuals murdered by oppressive regimes, has my sincerest admiration. Similarly, I have great respect for Kathleen M. Foley, M.D., and her work over decades as an important voice for compassion through advancing palliative and end-of-life care. Her life-affirming work has led to relief of suffering for countless numbers of people with chronic pain. So many heroes!

The United Kingdom's "Athena SWAN" Program for Advancing Women in Science Provides Model for Canada and the United States

Scientific institutions in Canada and the United States have drawn inspiration from the United Kingdom's Athena **SWAN** (Scientific Women's Academic Network) program. This program aims to advance women in scientific and other academic careers by certifying higher education institutions that adopt equitybased standards and practices and reach associated benchmarks.¹ Advance Higher Education, a nonprofit company based in York, England, administers the Athena SWAN program and awards qualifying departments, colleges, and universities gold, silver, or bronze accreditation based on their adherence to program guidelines. Established in 2005, Athena SWAN first acknowledged higher education programs in science, technology, engineering, mathematics, and medicine (STEMM) that advanced the careers of women. The program has since expanded to include the arts, humanities, social sciences, business, and law and to address a broader range of gender equity issues. An independent report from a research team at Loughborough University² and other research³ demonstrates the effectiveness of the Athena SWAN program to effect substantive systemic and cultural changes, including, notably, increasing representation of women in key roles and senior positions. In 2011, the Chief Medical Officer of the United Kingdom established requirements for academic departments to hold at least a silver award from Athena SWAN to qualify for funding from the English National Institute for Health Research. Athena SWAN has certified over 700 institutions in the United Kingdom and initiated pilot programs in Ireland and Australia.4

Last summer, representatives of Advance Higher Education met with Kirsty Duncan, Ph.D., who holds two Canadian cabinet ministry positions as Minister of Science and Minister of Sport and Persons with Disabilities, to discuss the establishment of Athena SWAN in Canada. Canada's Natural Sciences and Engineering Research Council plans to launch a pilot project sometime this year, and the Canadian government will provide grant support to institutions attempting to meet equity, diversity, and inclusion goals in line with Athena SWAN benchmarks and practices.

In January 2018, the American Association for the Advancement of Science (AAAS), with support from the Alfred P. Sloan Foundation and the Heising-Simons Foundation, announced the launch of the STEM Equity Achievement (SEA) Change initiative. Like Athena SWAN, SEA Change establishes equity-based standards and practices and will recognize higher education institutions that meet them. However, SEA Change has a broader scope and will award departments and universities for equitable practices pertaining to women, racial and ethnic minorities, people with disabilities, and marginalized populations. After a year of preparation and development, SEA Change has initiated its first phase, a "bronze award" pilot program involving

several undergraduate institutions, historically Black colleges, and other universities, including Carnegie Mellon University. SEA Change hopes to emulate the success of the Athena SWAN program, particularly in increasing diversity in the student body, faculty, and leadership of STEM departments and universities; in improving understanding and engagement from institutional leadership on issues related to inequity; and in increasing funding and data collection to address barriers to equitable advancement in STEM educational programs. In addition to accreditation, the SEA Change initiative will serve as a research repository for evidence and best practices related to educational equity, will provide training, will bring together multisector stakeholders to address equity issues in higher learning and provide funding to researchers and institutions, and will increase the size, depth, and diversity of the STEM workforce.

- 1. Rosser et al. 2019. Lancet 393: 604-608.
- 2. Munir et al. 2014. Evaluating the Effectiveness and Impact of the Athena SWAN Charter. Equity Challenge Unit, Loughborough University. Leicestershire, U.K.
- 3. Ovseiko et al. 2017. Health Res. Policy Syst. 15: 12.
- 4. <u>Latimer et al. 2019. Lancet 393:</u> 524-526.



Mentoring Program Advances Women of Color Scientists

(Original article by <u>Starlard-Davenport et al. 2018. Ethn. Dis. 18:</u> <u>575-578.</u>)

A group of scientists, all women of color from diverse backgrounds, describe their experience with the Programs to Increase Diversity Among Underrepresented Individuals Engaged in Health-Related Research (PRIDE) mentoring program of the National Heart, Lung, and Blood Institute (NHLBI). Led by African-American scientist and physician Betty Pace, M.D., the PRIDE mentoring program matches junior minority scientific researchers with senior mentors and enables PRIDE mentees to serve as peer advisors to one another. The program's goals include helping junior faculty develop and secure funding for independent research projects and to advance their careers at academic institutions by obtaining tenure track positions and moving toward full professor status. The scientific literature has established the value of mentoring in biomedical research careers, and both mentors and mentees in this program posit that PRIDE's "Sister's Keeper" paradigm works well to help women of color overcome cultural and systemic barriers for the betterment of science and public health.

Investigators Promote Gender Diversity in Methodology, Areas of Inquiry, and Research Teams

(Original article by <u>Nielsen et al. 2018. Nat. Hum. Behav. 2:</u> 726-734.)

Many members of the biomedical community promote gender diversity in the composition of research teams. However, commentators from Aarhus University, Denmark, and Stanford University seek to expand the role of gender diversity in the sciences by calling for greater gender diversity in research methods and questions as well. The researchers explain that gender-diverse research methods involve "gender and sex analysis" (GSA) as defined by Stanford University, an approach that coincides with NIH's Sex as a Biological Variable (SABV) policy. Both GSA and SABV call for researchers to incorporate sex and gender differences into their study designs, data collection and analyses, and reporting of results. The researchers also promote gender diversity in developing research questions. For instance, scientists might evaluate the effects of men entering roles historically occupied by women, such as nursing. Further, studies could consider how gender diversity within disciplines or areas of inquiry influence research agendas and the types of research questions posed. The researchers conclude by proposing a model of how their three approaches to gender diversity—in research teams, in research methodology, and in research questions—can function in distinct but interrelated domains: research teams, disciplines, research organizations, and society.

Pediatric Orthopedic Surgeon Calls for Parental Leave Policies for Medical Residents

(Original article by Laura Forese. AAMC News. October 9, 2018.)

Laura Forese, M.D., M.P.H., recounts her experiences while pregnant with twins during her orthopedic surgical residency 27 years ago. While no formal family leave policy existed at her hospital at that time, Dr. Forese explains that she was fortunate to secure 6 weeks off, that she did not have to extend her residency as a result, and that she valued the time she had to bond with her babies. Today, family leave policies often do not cover medical residents. Dr. Forese finds this situation unacceptable because more women than men are now entering medical school and because women's medical residencies most often occur during their prime childbearing years. Dr. Forese, who now serves as Executive Vice President and Chief Operating Officer of New York Presbyterian Hospital as well as a faculty member at the Columbia University Vagelos College of Physicians and Surgeons, calls for comprehensive, paid maternal leave policies for medical residents to foster the development of the next generation of physicians. Doing so, writes Dr. Forese, will result in physicians with healthy families, satisfying careers, and work-life balance, which will, in turn, strengthen patient care.

Companies Experiment with Mandatory Paternity and Maternity Leave

(Original article by <u>Joanne Lipman</u>. The Wall Street Journal. <u>September 28, 2018.</u>)

An essay in The Wall Street Journal calls for companies to follow the example of Humanyze, a Boston people-analytics firm, which requires employees who are new fathers to take 12 weeks of paid paternity leave. While some employers offer paternity leave, many men decide not to take it out of concern that it would impede their careers. Opting to forgo paternity leave results in an inequitable situation: new mothers take paid parental leave, often to the detriment of their careers, but men can opt not to. To overcome this systemic bias, a small number of companies offer men and women paid parental leave of equal duration and insist they take it. Over a third of U.S. companies offer some paid maternity leave, and many offer paternity leave as well. However, the United States remains the sole industrialized nation that does not require employers to offer paid family leave. Most American workers receive no paid family leave and benefit only from the 12 weeks of unpaid family leave guaranteed by the 1993 Family and Medical Leave Act. Further, research has shown that mothers suffer Continued on page 17



from a "motherhood penalty," a 4% reduction in earnings after the birth of a child, whereas men receive a 6% increase or "fatherhood bonus," an unfair situation resulting primarily from employer bias. The essay argues that mandatory paid paternity leave does not constitute a panacea but does take steps toward reducing workplace inequities.

A Personal Journey Alondra Nelson, Ph.D.

On January 16, Dr. Nelson, a sociologist known for her work on the intersections of science, technology, and social inequality, spoke to the Women of Color (WOC) Committee of the NIH Working Group on Women in Biomedical Careers and shared her experiences as a scientist and woman of color. She also shared her experience of growing up in a "White space" in San Diego, CA, a city with an active scientific community, where she learned the skills she used to navigate lvy League circles.

Alondra Nelson, Ph.D., Professor of Sociology at Columbia University, President of the Social Science Research Council

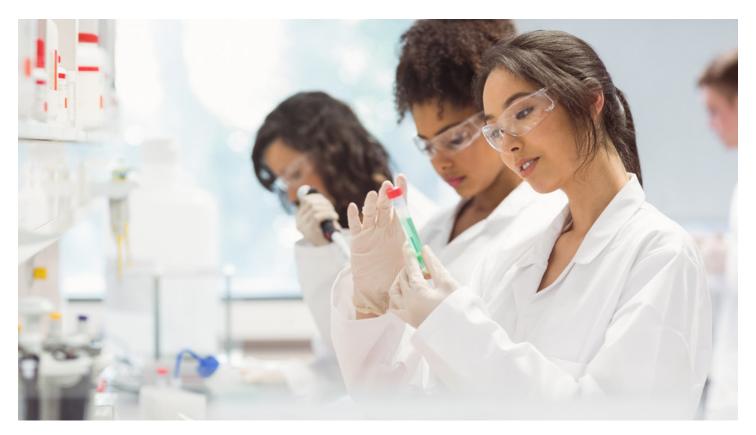
She described how some of her past positions—as the inaugural Dean of Social Science for the Faculty of Arts and Sciences at Columbia and as the Director of the Institute for Research on Women, Gender, and Sexuality, traditional, patriarchal organizations that had never been chaired by a woman or person of color—have informed the work she does now as President of the Social Science Research Council. Additionally. she lamented how scholars from underrepresented groups feel less freedom of expression

and must often understate their positions for fear of being misunderstood. Dr. Nelson also outlined her intention of using her role as President of the Social Science Research Council to develop ethical principles to guide global collaborations in social science research and to overcome the mistrust that sometimes exists between social scientists of developed countries and those in developing countries.

After the WOC meeting, Dr. Nelson, as part of the prestigious NIH Wednesday Afternoon Lecture Series (WALS), delivered a speech on The Social Life of DNA, also the title of her 2016 book. She spoke on the popularity of genealogy and genetic testing among African Americans and how these DNA-based techniques have expanded beyond personal hobbies to involve race, the history of slavery, cultural ancestry, and legal claims for reparations. Dr. Nelson is also the author of Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination.



(Left to right) Deputy Director of NIA and Chair of the WOC Committee Marie Bernard, M.D.; Dr. Nelson; and ORWH Director Janine Austin Clayton, M.D.



The Lancet Publishes and Promotes Women in Science Special Issue

The Lancet published a special double-length issue on "Advancing Women in Science, Medicine, and Global Health" (Volume 393, Issue 10171), which explores the institutional and systemic barriers faced by women in science and presents evidence of bias within scientific systems and institutions. Articles and perspectives in this issue also describe ways to confront gender bias, increase diversity, and prevent workplace harassment. The Lancet promoted this special publication with speeches and presentations by noted scientists, physicians, and policy experts at events in London on February 8 and in New York at Columbia University on February 11, the latter cosponsored by the Helmsley Charitable Trust. ORWH Director Janine Austin Clayton, M.D., gave a speech titled "Workforce Equity Paves the Way for Better Science and Health Equity" at the New York event. She discussed how integrating sex and gender influences into preclinical studies, clinical trials, cell and animal studies, and implementation studies improves evidence-based health care for all; how a diverse, wellinformed biomedical workforce yields better science and health; and how gender diversity leads to better outcomes in all professional contexts, including biomedical research. Dr. Clayton described how the themes raised by this special issue of The Lancet coincide with those of Advancing Science for the Health of Women: The 2019-2023 Trans-NIH Strategic Plan for Women's Health Research. Dr. Clayton also recently co-authored "Integrating Sex and Gender Considerations in Research:

Educating the Scientific Workforce" for *The Lancet: Diabetes* & *Endocrinology.* (Regensteiner et al. 2019. *Lancet Diabetes Endocrinol.* doi: 10.1016/S2213-8587(19)30038-5.)

U.N. Celebrates International Day of Women and Girls in Science

On February 11, the United Nations Educational, Scientific, and Cultural Organization celebrated the International Day of Women and Girls in Science to promote the involvement of women and girls in STEM education and research. First celebrated in 2015, the International Day of Women and Girls in Science is observed in over 68 nations. This year, the U.N. headquarters in New York hosted a summit titled "Investment in Women and Girls in Science for Inclusive Green Growth" on February 11 and 12. The full program and recordings of the panel discussion are available at the holiday's dedicated website: www.womeninscienceday.org.

NIH Sponsors Webinar on Female Genital Mutilation

On February 20, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development and ORWH cosponsored a webinar about research on and treatment of female genital mutilation/cutting (FGM/C). FGM/C comprises all procedures involving partial or total removal of the external female genitalia or other injury to the female *Continued on page 19*

genitals for nonmedical reasons. Estimates from the Centers for Disease Control and Prevention show increases in the practice of FGM/C and in the number of women and girls affected by FGM/C in the United States. In the webinar, Crista Johnson-Agbakwu, M.D., addressed strategies to improve health outcomes for refugee women, particularly those who have undergone FGM/C or experienced sexual violence. This webinar was the first in a series on the effects of sex and gender influences among populations of women who are understudied, underrepresented, and underreported—the U3 populations—in biomedical research.

ORWH Director Speaks on Maternal Health Racial Disparities at Event Honoring Dr. Shalon M. Irving



Dr. Shalon M. Irving Photo Credit: Johns Hopkins Bloomberg School of Public Health

On February 25, ORWH Director Janine Austin Clayton, M.D., spoke at the Johns Hopkins Bloomberg School of Public Health (JHSPH) at a symposium titled "The Fierce Urgency of Now: Honoring the Legacy of Dr. Shalon M. Irving and Advancing the Agenda to Eliminate Racial Disparities in Maternal Health." In 2017, Dr. Irving, a Lieutenant Commander in the U.S. Public Health Service

Commissioned Corps, an epidemiologist with CDC, and an alumna of JHSPH, died from high blood pressure complications at the age of 36, just weeks after giving birth to her daughter. Dr. Clayton spoke about health care disparities, particularly how Black women are three to four times more likely to die of pregnancy-related causes than White women, and about programs and research efforts sponsored by NIH, ORWH, and others to address these disparities.

NIH, the National Science Foundation, and the L'Oréal Foundation Sponsor the National Academies of Sciences, Engineering, and Medicine (NASEM) Study on the Underrepresentation of Women in Science

On March 11, the NASEM Committee on Women in Science, Engineering, and Medicine held an event titled "A Symposium Highlighting Evidence-Based Interventions to Address the Underrepresentation of Women in Science, Engineering, and Medicine" at the National Academy of Sciences in Washington, DC. The symposium was part of a new consensus study addressing institutional barriers preventing women from

pursuing successful science careers and examining policies, practices, and strategies that have been effective in opening doors to women in the sciences. Representative Donna Shalala, Ph.D., former Secretary of Health and Human Services and representative of Florida's 27th Congressional District, delivered the keynote address. She was introduced by Vivian Pinn, M.D., the first full-time Director of ORWH. Current ORWH Director Janine Austin Clayton, M.D., participated in a panel on scientific agencies and foundations designed to improve women's representation in the sciences. The study committee of the NASEM consensus project is chaired by Mae Jemison, M.D., a former NASA astronaut and the first African-American woman to travel into space.

NIH Sponsors Seminar on Influenza and Sex as a Biological Variable

On March 13, Sabra L. Klein, Ph.D., Associate Professor of Molecular Microbiology and Immunology at the Johns Hopkins Bloomberg School of Public Health and a principal investigator in the Specialized Centers of Research on Sex Differences (SCORE) program, led a seminar titled "Sex as a Biological Variable in Influenza Pathogenesis and Vaccine-Induced Immunity." The event was sponsored by the Cell Biology Interest Group of the National Heart, Lung, and Blood Institute (NHLBI) and held on the NIH main campus. Dr. Klein's research explores the mechanisms mediating how men and women differ in their responses to viral infection and vaccination; the potential role that sex steroids play in modulating immune responses to viruses; and how immunological, hormonal, and genetic differences between men and women affect their susceptibility to influenza and other viruses.

NIH Scientific Interest Group (SIG) on Sex and Gender in Health and Disease (SGHD)

On March 19, the SGHD SIG met on the NIH campus to discuss sex and gender differences in the carcinogenesis and treatment of gastric cancer, the third leading cause of cancer deaths worldwide. Maria Constanza Camargo, Ph.D., an Earl Stadtman Tenure-Track Investigator in the Division of Cancer Epidemiology and Genetics at the National Cancer Institute (NCI), shared her current research in the Metabolic Epidemiology Branch, where she maintains a robust research program with a multidisciplinary team of international collaborators applying cutting-edge molecular epidemiology to the study of *Helicobacter pylori* and premalignant and malignant gastric lesions.

ORWH Hosts 48th Meeting of the NIH Advisory Committee on Research on Women's Health (ACRWH) Featuring the HEAL Initiative



On April 10, ORWH hosted ACRWH's meeting at the Natcher Conference Center on the NIH Main Campus in Bethesda, MD. Director of the National Institute on Drug Abuse (NIDA) Nora D. Volkow, M.D., gave the keynote address in which she described the Helping to End Addiction Long-term (HEAL) Initiative and NIDA-supported research addressing sex differences in pain and addiction. Launched in April 2018, the HEAL Initiative builds on NIH research on pain and addiction and on integrating behavioral interventions with medication-assisted treatment to improve treatments for opioid use and addiction and to enhance pain management. You can view the meeting on the NIH Videocast page and read a summary on the ORWH website.

Protective Effects Against Breast Cancer Begin Only Decades After Childbirth

Women who have given birth have a lower risk of developing breast cancer than women who have not. However, NIH scientists at the National Institute of Environmental Health Sciences (NIEHS) and colleagues recently found that mothers may not realize this protective effect for 20-30 years after their last pregnancy. In fact, the investigators, compiling results from 15 studies involving almost 900,000 women younger than 55, reported that the risk of developing breast cancer may remain slightly elevated for much of this time. The years immediately following childbirth represent the period of greatest risk, peaking approximately 5 years postpartum. The researchers found no protective effect of breastfeeding, commonly thought to reduce the likelihood of developing breast cancer. The study also found that risk increased for women who were of greater maternal age at first birth, who had more births, or who had a family history of breast cancer. Although a few earlier studies had identified this increased risk in the years after childbirth, the NIEHS results challenge many beliefs about the protective effects of pregnancy and breastfeeding. However, most studies

involving breast cancer risk have involved only postmenopausal women, which may explain the discrepant results. Breast cancer remains uncommon in younger women and is difficult to study in this population. As such, the researchers caution against alarmism but advise care providers to consider these findings in treating young women. (Nichols et al. 2018. Ann. Intern. Med. 170: 22-30.)

National Cancer Institute Tests 3-D Mammography Technology

NCI has initiated a 2½-year randomized breast screening trial to compare the efficacy of standard 2-D digital mammography, which takes two pictures of the breast and yields a flat image, with that of a newer technology called tomosynthesis mammography, which takes multiple pictures of the breast to build a 3-D image. The Tomosynthesis Mammographic Image Screening Trial (TMIST) will enroll nearly 165,000 women aged 45-74 and will help researchers determine the best ways to detect breast cancer in asymptomatic women. TMIST will compare the cumulative rates of advanced breast cancer in women who undergo both tomosynthesis and standard digital mammography with those of women who undergo standard digital mammography alone. The TMIST project will also build a bank of blood, buccal (mouth) swab, and other tissue samples for future research to assess how genetics and other personal risk factors can inform future breast cancer screening practices. Additional information on TMIST is available on the NCI website.

The New York Times Quotes NIH Director on the Healing Power of Music



NIH Director Francis Collins, M.D., Ph.D., was quoted in *The New York Times* about the healing power of music and NIH's partnership with the John F. Kennedy Center for the Performing Arts called <u>Sound Health: Music and the Mind.</u> Dr. Collins coauthored an article for *JAMA* with Renée Fleming, M.M., a famous soprano and artistic advisor to the Kennedy



Center, on the therapeutic potential of music for patients with some neurological conditions, such as Broca's aphasia. Research shows that music can also decrease depressive symptoms, lower blood pressure, and reduce pain. Sound Health arranges explorative collaborations between musicians and neuroscientists, and Dr. Collins hopes that researchers will investigate the potential of music in the treatment of mental health conditions. The *Times* article also describes orchestra conductor Ronald Braunstein, who uses music to help treat his bipolar disorder. To raise awareness and help destigmatize mental health issues, Mr. Braunstein founded a nonprofit organization to establish orchestras in which all the performers have been affected by mental illness. (Hollow, M.C. "Fighting the Stigma of Mental Illness Through Music." *The New York Times* 01-29-2019; Collins and Fleming. 2017. JAMA 317: 2470-2471.)

ORWH Associate Director Publishes Article on Adapting Interventions for Health Disparity Populations

ORWH Associate Director Victoria Cargill, M.D., coauthored an article titled "Building the Evidence Base to Inform Planned Intervention Adaptations by Practitioners Serving Health

Disparity Populations," recently published in the American Journal of Public Health. The article explores how practitioners often adapt medical evidence-based interventions better to suit the needs of patients in diverse community settings, particularly low-resource settings serving health disparity populations. While such adaptations can be effective, documentation and evaluation of these adaptations are rare. The article presents research strategies on practitioner-led adaptations to facilitate successful and equitable adaptation, implementation, and delivery of evidence-based interventions. (Alvidrez et al. 2019. Am. J. Public Health 109: S94-S101.)

ORWH Director Interviews with NBC's *Today* Show on Maternal Morbidity and Mortality

Gabrielle Frank from NBC's *Today Show* interviewed ORWH Director Janine Austin Clayton, M.D., on February 27. They discussed the problem of maternal morbidity and mortality in the United States, associated racial and ethnic disparities, and efforts by NIH as well as other medical and legislative organizations to address the problem. *The Today Show* will broadcast the interview sometime in April and post it on the show's <u>website</u> (www.today.com).



DawnKimberly Hopkins, Ph.D., joined ORWH in October 2018 as a visiting post-doctoral fellow in the Science Policy, Planning, and Analysis section, where she will contribute to the implementation and evaluation of The Trans-NIH Strategic Plan for Women's Health Research as well as a research program and policy directives on polycystic ovarian syndrome, her primary research interest. She earned her doctoral degree through the Air Force Institute of Technology and her Master of Nursing from Old Dominion University. Dr. Hopkins serves as a Lieutenant Colonel in the U.S. Air Force and was deployed to Afghanistan, where she earned the Bronze Star Medal for her service. She has worked as a registered nurse and nurse practitioner in civilian and military medical positions in a variety of medical fields including obstetrics, gynecology, urology, oncology, and mental health.



Teraya Donaldson, Ph.D., joined ORWH in August 2018 as an AAAS Science Technology Policy Fellow. Dr. Donaldson currently works on inclusion and policy projects under ORWH's Science Policy, Planning, and Analysis section. She also works on training programs within ORWH and serves as the Executive Secretary for the NIH Working Group on Women in Biomedical Careers. She earned her doctoral degree from Albert Einstein College of Medicine, where she investigated a protein involved in malaria metabolism. In her postdoctoral training, Dr. Donaldson studied how temperature and pressure affect protein folding of alpha helical peptides. She also earned an additional fellowship during which she designed bacterial whole-cell biosensors that report the presence of chemicals with fluorescence for diagnostic applications. Previously, Dr. Donaldson taught at Columbia University, Oberlin College, the University of Richmond, and Virginia Commonwealth University.



Régine Douthard, M.D., M.P.H., joined ORWH in 2018 as a Senior Program Officer and serves the ORWH leadership as a Senior Medical officer and as a subject matter expert in women's and global health. Before joining ORWH, she worked in the Environmental Influences on Child Health Outcomes program, the National Institute of General Medical Sciences, and the former National Center of Research Resources. She earned her doctoral degree at the University of Health Sciences, Libreville, Gabon, and an M.P.H. at Emory University. She completed a residency in Family Medicine and a Fellowship in Environmental and Occupational Medicine at George Washington University Hospital. Before joining NIH, Dr. Douthard worked with USAID and the Health Resources & Services Administration's Global HIV/ AIDS Program. She has received the Health and Human Services Secretary's Award and the NIH Director's Award.

TEAMING UP FOR WOMEN'S HEALTH

PregSource® is an online platform to improve knowledge of how women experience pregnancy and new motherhood. Led by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development—in partnership with ORWH and other organizations—PregSource® asks pregnant women to share what they are seeing, thinking, and feeling during pregnancy and after giving birth. All responses are captured securely through a free, confidential website. This crowdsourcing project promises to help researchers answer questions about pregnancy and improve care for future moms-to-be. For more information, visit the PregSource® website.



Additional Reading on Maternal Morbidity and Mortality

Continued from page 6

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Advancing Science for the Health of Women: The NIH Office of Research on Women's Health A Symposium at the Organization for the Study of Sex Differences (OSSD)/International Society for Gender Medicine (IGD) Joint Meeting 2019 ORWH Symposium: May 5, 2019,

10:00 a.m.-12:00 p.m.

Joint Meeting: May 5–8, 2019 Washington Marriott Georgetown Washington, DC

20th Anniversary of National Women's Health Week May 12–18, 2019



4th Annual NIH Vivian W. Pinn Symposium— Improving Maternal Health: Behind the Numbers May 15, 2019 12:00 p.m.-4:30 p.m. (Eastern Time) NIH Main Campus Wilson Hall

49th Meeting of the NIH Advisory Committee on Research on Women's Health October 23, 2019 9:00 a.m.-4:00 p.m. (Eastern Time) Main NIH Campus Natcher Conference Center For more information, please visit www.nih.gov/women.

ORWH and NIH Funding Opportunities

Research Supplements to Promote Re-Entry into Biomedical and Behavioral Research Careers

ORWH and participating Institutes and Centers (ICs) of NIH announce the continuation of the program to support individuals with high potential to re-enter an active research career after an interruption for family responsibilities or other qualifying circumstances. Application due dates vary based on participating IC. For more information, see FOA number PA-18-592 or contact ORWH at ORWHinfo@nih.gov.

Accelerating the Pace of Child Health Research Using Existing Data from the Adolescent Brain Cognitive Development (ABCD) Study

The ABCD Study is collecting data on health and mental health, cognitive function, substance use, cultural and environmental factors, and brain structure and function from youths starting at 9–10 years of age and following them to early adulthood. This announcement encourages applications proposing analysis of this dataset to increase knowledge of adolescent health and development. For more information, visit the ABCD Study web page (www.abcdstudy.org)

NIH Office of Research on Women's Health (ORWH)