

Congressional Briefing

Prostate Cancer, Breast Cancer: The Patient Experience

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Agenda

Prostate Cancer, Breast Cancer: The Patient Experience

Armin Brott moderates

11:00 am - Armin Brott opens and introduces Congressman Payne, Jr.

Congressman Donald Payne, Jr. addresses the briefing

11:10 am - Prostate Cancer (PCa) segment -

ZERO representative talks about the patient experience

Pat Sheffler is from San Diego

Men's Health Network representative talks about the patient experience

Reginold "HOLLYWOOD" Thompson, a native of Memphis, Tennessee

11:30 am - *Improving the Outcome of Men with Prostate Cancer*

William L. Dahut, M.D.

Chief, Prostate Cancer Clinical Research Section

Genitourinary Malignancies Branch

Center for Cancer Research

National Cancer Institute

11:45 am - Breast Cancer (BCa) segment -

HealthyWomen representative

Missy Peters, Founder

Breast Cancer Portrait Project

12:05 pm - Q & A

12:10 pm - Closing Remarks, Armin Brott

Speaker Bios –

Donald M. Payne, Jr. (NH-10)

U.S. Representative Donald M. Payne, Jr. is a Democratic congressman representing New Jersey's 10th Congressional District, which covers portions of Essex, Hudson, and Union counties. A Newark, New Jersey native, he has served the people of the 10th Congressional District since 2012. Rep. Payne, Jr. is a tireless fighter for New Jersey families, working to create jobs and grow the economy, protect and invest in our children, and ensure the health and safety of our communities.



In 2021, Rep. Payne, Jr. was voted to be Chairman of the Subcommittee on Railroads, Pipelines and Hazardous Materials in the powerful House Committee on Transportation and Infrastructure. The Committee has jurisdiction over national infrastructure and all modes of transportation, including aviation and mass transit.

Rep. Payne, Jr. is a strong supporter of the Affordable Care Act, which provides thousands of New Jerseyans with access to high-quality, affordable health care. He has been a strong advocate for investing in and protecting the health of our children and introduced the TEST for Lead Act to protect children from lead-contaminated drinking water in schools. Rep. Payne, Jr. also is a vocal advocate for cancer prevention, introducing the National Colorectal Cancer Awareness Month Resolution to raise awareness about the need for regular cancer screenings.

Rep. Payne, Jr. began his long career in public service when he founded Newark South Ward Junior Democrats, becoming its first president. He also served as an adviser to the YMCA Youth in Government program. He attended Kean College (now Kean University), where he studied graphic arts. He lives in Newark with his wife Beatrice and their triplets, Donald III, Jack, and Yvonne.

[Read more about Congressman Payne, Jr. here.](#)

Armin Brott, [Mr. Dad](#), MBA

Hailed by *Time* Magazine as "the superdad's superdad," Armin Brott has been building better fathers for more than a decade. As the author of eight bestselling books on fatherhood, he's helped millions of men around the world become the fathers they want to be—and that their children need them to be. His books include [The Military Father](#), which gives deployed dads and their families the tools they need to maintain strong relationships before, during, and after deployment.



He also writes two nationally syndicated newspaper columns, "Healthy Men" and "Ask Mr. Dad" and also edits the popular [Talking About Men's Health](#) blog.

He has written for *The New York Times Magazine*, *Newsweek*, *American Baby*, *Parenting*, *Child*, *Men's Health*, *The Washington Post*, and dozens of other major publications and websites.

Armin has been a guest on hundreds of radio and television shows, including Today, CBS Overnight, Fox News, and *Politically Incorrect*, and his work on fatherhood has been featured in such places as *Glamour*, *Time*, *The New York Times*, *The Chicago Tribune*, *Newsday*, and many others.

Armin is the host of "Positive Parenting," a weekly radio program which airs on the American Forces Network and reaches more than 2 million service members worldwide.

He is active in the Men's Health Caucus of the American Public Health Association and was elected to the Communications position.

William L. Dahut, M.D.
CCR Scientific Director for Clinical Research
National Cancer Institute

Dr. Dahut received his M.D. from Georgetown University in Washington, DC. He completed clinical training in internal medicine at the National Naval Medical Center in Bethesda, MD, followed by training in hematology and medical oncology at the Bethesda Naval Hospital and the Medicine Branch of the NCI. Dr. Dahut worked as an attending physician in the NCI-Navy Medical Oncology Branch until 1995. He then joined the faculty of the Lombardi Cancer Center at Georgetown University before returning to NCI in 1998. Dr. Dahut's primary research interest has been in the development of novel therapeutic strategies for the treatment of adenocarcinoma of the prostate. He has pioneered the effort to combine experimental therapies such as angiogenesis and immunotherapy with chemotherapy, androgen blockade, radiotherapy and other more traditional modalities. His recent studies combining immunotherapy with more standard treatment have been active and demonstrated the ability to maintain a robust immunologic response.



In 2009, Dr. Dahut was appointed as CCR Clinical Director where he oversees and assures the quality of medical care delivered to patients participating in CCR clinical trials. In 2012, Dr. Dahut was appointed as a CCR Deputy Director then in 2016 was selected to become the CCR Scientific Director for Clinical Research.

Pat Sheffler

Pat Sheffler is a husband, father, entrepreneur, philanthropist, ZERO Champion, and prostate cancer hero. In 2018, Pat was a fitness buff surrounded by a healthy family when he was diagnosed with aggressive prostate cancer following a life insurance exam. With the help of his family, Pat became his own best advocate, doing research, seeking out the experiences of others, and exploring every option to find the prostate cancer treatment option that today has left him prostate cancer-free.



Today, Pat is in the best shape of his life and credits his healthy lifestyle and commitment to fitness. But the single biggest thing that's gotten him through his prostate cancer ordeal is his attitude – "every single human being will have challenges in life and it really comes

down to how we will handle them.” Pat has handled his challenges like a champion – a champion who has become an inspiration to his family and his community by not only beating prostate cancer, but also dedicating himself to sharing his story, educating other men, advocating for early cancer detection, and raising funds to beat the disease.

Pat lives in San Diego, CA, with his wife Caren. He has three grown children and spends his time running his business, playing sports, and staying active. Pat’s biggest joy in the world is spreading awareness (and advocating for early detection of all cancers) and love (and of course, spending time with his family). #shefflerstrong #positivevibes

Reginold "HOLLYWOOD" Thompson

Reginold "HOLLYWOOD" Thompson, a native of Memphis, Tennessee, is a husband, and father of four.

He is an adamant motorcycle rider and a member of "HELL LOVER'S" motorcycle club. As well as a former disc jockey.

But, more importantly, he has survived two diagnoses of Prostate Cancer. At 64 years of age, he did not start out believing he could survive for 10 years!

Hollywood works with Judy Seals-Togbo, MSW, Program Manager at Men's Health Network, to help promote prostate cancer awareness and screening across Tennessee and surrounding states.



Missy Peters

- Diagnosed at 34 while pregnant
- IDC Stage IIB, ER+
- BRCA1+
- Young Breast Cancer Advocate
- Breast Cancer Portrait Project: 501(c)3 founder and photographer (www.breastcancerportraitproject.org),
- [@breastcancerportraitproject](https://www.instagram.com/breastcancerportraitproject) on instagram



Missy was initially misdiagnosed with a fibroadenoma while 6 weeks pregnant. Her Stage II diagnosis came a few days before her daughter was born full-term. Her doctors told her she was “too young” for breast cancer at 33-34 years old. Missy learned she carries the BRCA1 gene mutation despite no family history of breast cancer. She started the Breast Cancer Portrait Project, 501(c)3, to raise awareness that “Young Women Get Breast Cancer Too”. She has interviewed and photographed approximately 70 women (and counting) who were diagnosed before 40. She wishes to bridge communication with the medical community to remind physicians that no woman is “too young” for breast cancer. Missy has a Master’s in Prosthetics and Orthotics from Georgia Tech and works part time as a prosthetic clinician for amputees.

Organizations –

[National Cancer Institute, Center for Cancer Research](#)

[Centers for Disease Control and Prevention, Division of Cancer Prevention and Control](#)

[American Urological Associations](#)

[Breast Cancer Portrait Project.](#)

[Fans for the Cure](#)

[HealthyWomen](#)

[Men's Health Network](#)

[ZERO – The End of Prostate Cancer](#)

Helpful Links -

[Prostate Cancer Awareness Month](#)

[Male Breast Cancer Resource Center](#)

[Men's Health Resource Center](#)

[Patient-Centered Outcomes Research Institute](#)

[Prostate Cancer: Evidence Update for Patients](#)

How Will Treating My Early-Stage Prostate Cancer Affect My Quality of Life?

[Prostate Cancer: Evidence Update for Clinicians](#)

[Helping Women with Breast Cancer Choose between Surgical Treatment Options](#)

[Get It Checked](#)

Screening suggestions for men and for women.

[After a Breast Cancer Diagnosis, Strap In for a Roller-Coaster Ride of Emotions](#)

[Options for Breast Reconstruction](#)

[Breast Cancer Is the Leading Cause of Cancer Death in Latina Women: The Healthcare System Could Change That](#)

[Fast Facts: What You Need to Know About Genetics and Breast Cancer Risk](#)

[What You Need to Know About Menopause and Breast Cancer](#)

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Congressional Briefing

Prostate Cancer, Breast Cancer: The Patient Experience

September 30, 2021 – 11:00 am – 12:15 pm

Statement of Missy Peters

Breast Cancer Survivor

Good Morning, My name is Missy Peters and 2.5 years ago I was *finally* diagnosed with breast cancer at the age of 34. I say *finally* because it took 11 months to get diagnosed. In fact, I carried my first and only baby full term during this time. I was under the care of a Primary Care Physician, an OBGYN, and a radiologist who all overlooked my lump or reassured me that at 33 *then* 34, that I was “too young” for breast cancer, and my lump was benign.



I've blamed myself and felt *stupid* in the years since my diagnosis. I internalized this delay as *my fault* and frankly, I'm convinced that's exactly how our healthcare system is designed to work... The young woman must advocate for herself...

...I'll get to that more in a moment.

You see, I had no family history of breast cancer and was under the impression that I was not at risk. Mammogram campaigns and pink ribbons seem to synonymously start with turning 40. What I can tell you is I've checked the boxes for ovarian and pancreatic cancer on every medical history form I've filled out to establish care with new physicians for years – including the OBGYN and PCP who overlooked my lump. Turns out, these were red flags that I may carry the BRCA1 gene mutation that would elevate my risk of cancer to 80%.

But as far as I'm concerned, no one ever looked at my medical history forms, because I found out I carry the BRCA1 gene mutation a week after giving birth to my daughter and a week and a half after my cancer diagnosis.

My maternity leave turned into my extended short term disability leave from work. I went from delivering a baby into clinically induced menopause within 2 weeks. Hey, here's a silver lining - dads can feed formula fed babies so moms in chemo can get sleep.

My life was flipped and the anger towards our medical system was slowly surfacing.

How did I slip through the cracks? How did it take 11 months to get diagnosed? Why was I reassured I had nothing to worry about? Why did my OBGYN never touch my boobs, isn't that her job? Sadly, I've learned that it's not her job.

As ACOG + ACS have backed off of clinical and breast self exams, they unfortunately – in my strong opinion - have not backfilled the conversation with anything.

I've done my research. In July of 2017, ACOG released a bulletin updating former guidelines to endorse "breast awareness" instead of clinical and self exams. They wrote, and I quote, "Women *should* be educated about the signs and symptoms of breast cancer and advised to notify their health care provider if they notice a change such as pain, a mass, new onset of nipple discharge, or redness in their breasts". End quote.

This leaves me to ask the question, Who? Who is supposed to teach women "breast awareness"? That's great to write this, but if nobody is teaching us "breast awareness" and we no longer endorse breast exams, then who is looking out for us? In my strong opinion, no one.

While in treatment and still receiving disability to heal from my bilateral mastectomies, I started the Breast Cancer Portrait Project, a 501c3, to raise awareness that "Young Women Get Breast Cancer Too". I thought to myself, if I had just heard of 1 woman diagnosed with breast cancer before 40, I may have *urged* physicians to *help* me to get diagnosed sooner, I would have *advocated* for myself, instead of trusting them. Which is exactly how our medical system is designed to work. Remember that moment I put on hold? Our medical system puts the responsibility back on the young woman but has never educated her on breast health: signs, symptoms, and risks of breast cancer - or in ACOG's own words, "Breast Awareness".

Thus, I made it *my* responsibility to teach others. I never returned to work full time. Instead, I started working for free, photographing and sharing stories of women in the Young Breast Cancer community. I wish I could say that they are all survivors, but a number of stories are shared in memoriam, as our disease is more deadly and more likely to be diagnosed at later stages than in women over 40. In fact, 50% of the women I have randomly photographed for the Breast Cancer Portrait Project had delayed diagnoses. I say that again – 50% of the women I have photographed for the Breast Cancer Portrait Project had delayed diagnoses – this is congruent with Ruddy et al's data from 2009, presented at ASCO and cited in the EARLY Act. When I looked more closely at my data to see how so many young women could slip through the cracks I saw obvious trends. I saw that approximately 1/3 of these women had delayed diagnoses because they did not feel they were at risk for breast cancer so they did not go to the doctor; another 1/3 did go to the doctor but were sent home as the physicians were not concerned, stating they were "too young". And in the final group, an alarming 1/3 of young women with delayed diagnoses were dismissed by their radiologists *after* ultrasound imaging, being told it was a fibroadenoma, or benign mass – just like me. Here's another fact, 50% of us have no family history of breast cancer and were considered average risk. This is all kind of scary, isn't it. I'm sure many of you have daughters or granddaughters.]

Which brings me to *this* food for thought. If we know young women are routinely delayed in diagnoses, which they are, then why aren't our physicians holding their word of teaching us "breast awareness"? Or are they relying on nonprofits such as my own to do so? If so, where's the PSA and funding to support us? Or is that my job too?

A high school girl is memorialized in the Breast Cancer Portrait Project through her older sister who shared her story. Andi passed away at 16 years old of metastatic disease. She had no family history of breast cancer. Andi concealed her red and inflamed breast, even stuffed her sports bra with tissues to collect her nipple discharge

and hide her weird boob from her volleyball teammates in the locker room. By the time Andi's mom accidentally saw her changing and ushered her through a diagnosis, it was too late. She passed away that year.

Young women and frankly women of all ages deserve to *know* the signs, symptoms and risks of breast cancer. No physician should ever tell a woman of any age that she is "too young". Because although she is *just* their patient, she is somebody's daughter, somebody's wife, somebody's mother, and her life is *very* important to them.

Today - 3 and half years after finding my lump, my anger and sadness for the reality young women face has resurfaced. On Friday, my gynecologic oncologist told me that I may not be able to have another child. He will give me until December to see if my ovaries come back to life from the barren dryness that is ovarian suppression. But every year that passes my risk of ovarian cancer increases as I age closer to 40, because I carry the BRCA1 gene mutation.

I find myself thinking of all the doctors I saw prior to my diagnosis who never raised the alarm that I may be BRCA1 positive. Do they even read our medical history forms we fill out in their waiting rooms? If they had, my cancer diagnosis could have been avoided altogether, and I could have had prophylactic surgeries.

I think of the PCP who told me I just have lumpy boobs. I think of the OBGYN I saw repeatedly through my pregnancy who never touched my boobs. And I think of the radiologist who told me he was 95% confident my lump was a benign fibroadenoma and he wasn't worried. What was his name? Should I look it up and write him a letter? Should I tell him that he delayed my diagnosis by 11 months by providing me false reassurance? Would that have given my ovaries 11 more months to potentially come back to life, and offer my daughter a sibling?

What about the fact that roughly 1 in 3 of us who are currently cancer free, will be told again that we have cancer. Except this time it will have spread through our bodies and we will die from it. Because this is metastatic disease. I understand that I may not be able to make her a sister, but now I ask the question, how do those 11 months I lost affect my future? Because now this radiologist has affected whether my daughter will have a mother.

But this radiologist and none of these doctors have any idea who I am and how they have affected my life and my family's life. Because - that's the way our medical system works, and I was supposed to advocate for myself.

I thank you for the opportunity to speak this October eve. The Young Breast Cancer community and the Breast Cancer Portrait Project firmly believe that our collection of stories and anecdotal data shed light on the many necessary improvements that can be made by our medical system to protect our sisters and daughters.

We simply want our voices to be heard.

And we ask for those with power to hear us.

I thank you for this opportunity.

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