

Metastatic Breast Cancer

**MBC**alliance>

*together we are stronger than the disease*

# ADVOCACY SLIDE DECK

## SERIES 3 >>>

Challenges in Metastatic Breast Cancer:  
Big Issues That Could Change Lives

# MISSION

The mission of the Metastatic Breast Cancer Alliance is to extend life, to enhance quality of life, and to end suffering and death from MBC by advancing MBC research, improving access to quality treatments and care, empowering people through increased education and information about the disease, and access to available resources.

# SERIES 3

## Presentation Outline

- How many people in the US live with MBC?
- The improvement in breast cancer survival rates has slowed
- MBC research funding
- Addressing disparities in MBC
- Access to palliative care for MBC
- Patient Voices

# challenge

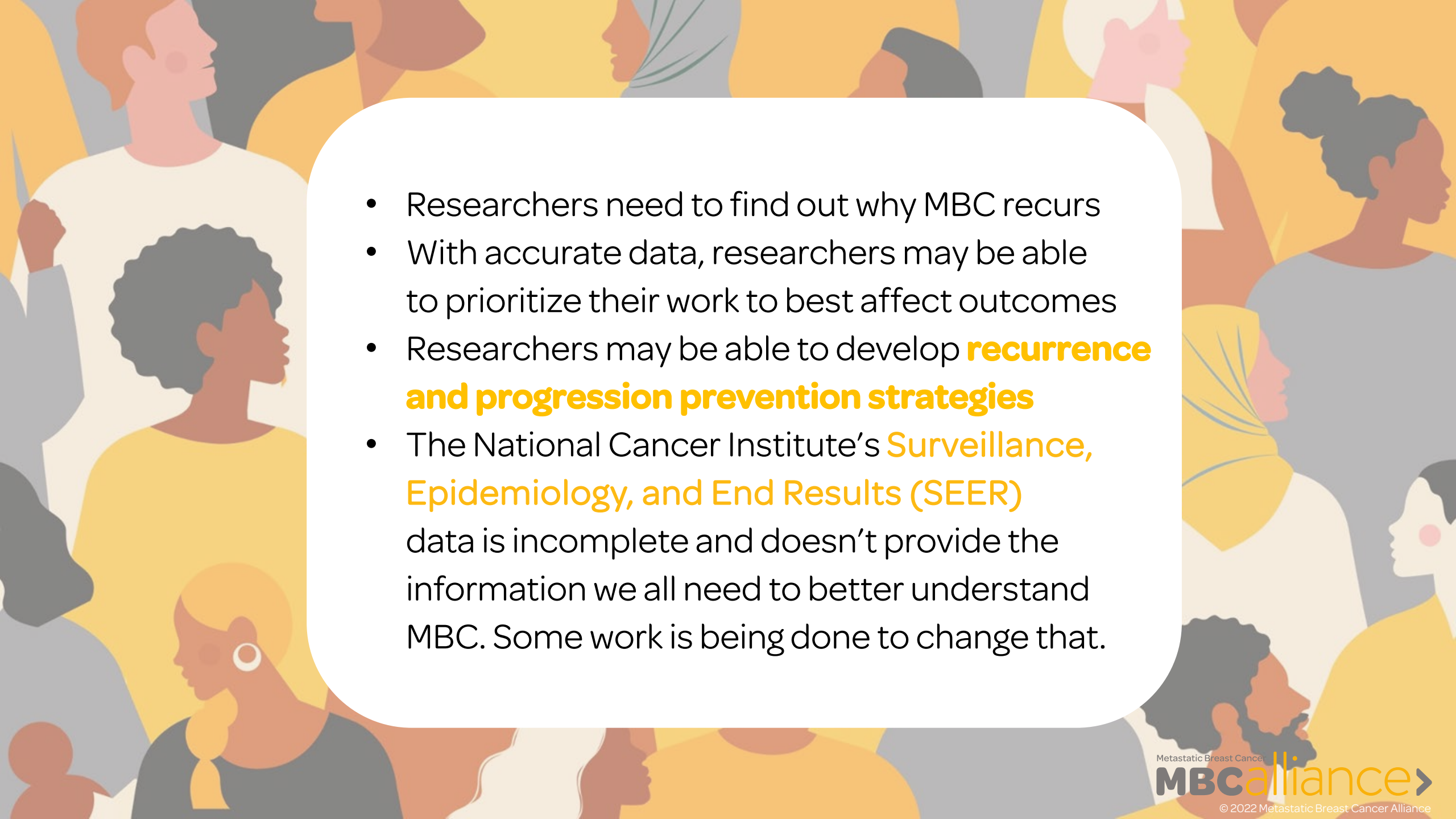
## How many people in the US live with MBC?

- **Currently, there are only estimates of how many women and men are living with MBC in the US**
- **Why is there no accurate total count?**
  - Only people who receive an MBC diagnosis as their first diagnosis are counted
  - People who receive an MBC diagnosis **after** being treated for early-stage breast cancer are **not counted**

# Counting every MBC patient is important because...



- What we do not count is **ignored**

- 
- Researchers need to find out why MBC recurs
  - With accurate data, researchers may be able to prioritize their work to best affect outcomes
  - Researchers may be able to develop **recurrence and progression prevention strategies**
  - The National Cancer Institute's **Surveillance, Epidemiology, and End Results (SEER)** data is incomplete and doesn't provide the information we all need to better understand MBC. Some work is being done to change that.

# challenge

## The improvement in breast cancer survival rates has slowed

- ASCO's website, [cancer.net](https://www.cancer.net), estimates that 43,250 women and 530 men in the US died from breast cancer in 2021
  - That is an average of 119 people **every day**
  - Women of all ages receive MBC diagnoses
  - Younger women and males are more likely to receive an MBC diagnosis as their first diagnosis
  - *Breast cancer is the second leading cause of death among Black/African-American women*
  - *Hispanic women have the highest mortality rate from breast cancer*

# challenge

## Deaths of so many women from MBC impact the socioeconomic well-being of the US

- Women are paid and unpaid workers in society
  - Mothers are often responsible for the well-being, care, and education of their children. Children are left behind without the love and guidance of women in their families
  - Younger women lose the opportunity to become mothers and wives
  - Women lose the opportunity to contribute to and advance in the workplace
  - Women of all ages also act as caregivers for others in and outside the home
  - Women comprise the majority of teachers and nurses in US society

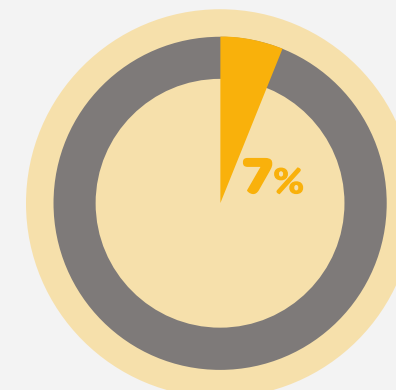


# challenge

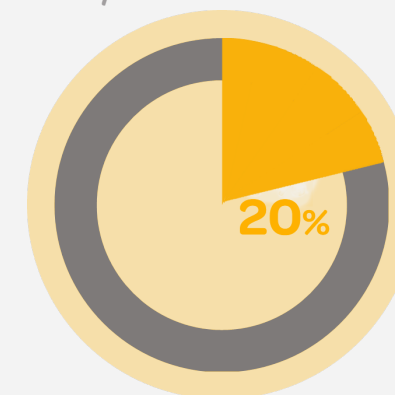
## MBC does not receive enough research funding

- Despite efforts to quantify the percentage of breast cancer research dollars going to MBC research, the most complete analysis to date comes from the 2014 MBC Alliance Landscape Analysis
  - Of \$15 Billion invested in governmental and major-nonprofit breast cancer research from 2000 to 2013 in North America and the United Kingdom, the MBC Alliance found that **only 7% was directed toward MBC**
  - The percentage of National Institutes of Health and Department of Defense/ Breast Cancer Research Program MBC research in fiscal year 2016 was estimated by the National Breast Cancer Coalition to be **approximately 20%**
  - The MBC Alliance is currently researching how that percentage has changed in recent years to determine if advocacy efforts have resulted in more research money going toward MBC

**\$15 Billion**  
Governmental and  
major nonprofit breast cancer  
research 2000-2013



NIH / DOD 2016



# Proposed Solutions

- Patient advocacy is key to changing research focus and outcomes
- Speak up for research that is focused on what matters to patients
- Consider becoming active in advocacy by participating in scientific projects and attending conferences

# challenge

## MBC needs focused research

With an estimated 43,780 people dying of MBC in the US each year, research to improve outcomes of those living with metastatic disease is crucial

*There are areas of great need...*

- **Including patient advocates** and nonprofit partners in research when asking what's needed to prevent death and improve quality of life
- Turning MBC into a disease that can be lived with for a full lifetime, with a good quality of life even if a cure is not attainable for all
- Preventing brain metastasis and central nervous system involvement
- Identifying better treatments for each subtype
- Overcoming treatment resistance
- Resolving care disparities, including those of race, age, gender, wealth, and location
- Establishing and improving supportive and palliative care access
- Supporting basic and translational science that may lead to new clinical trials
- Improving clinical trial design
- Including more representative patient participation in clinical trials

challenge

## Addressing disparities in MBC

- Across the country, disparities prevent many MBC patients from accessing high quality health care and affordable treatments
- These disparities include socioeconomic status, race, age, where people live, language, gender, sexual identity and orientation, and access to health care
- If these disparities are reduced, more patients might live longer than the current median 2-3 years

# Proposed Solutions

- The bipartisan [\*Telehealth Extension and Evaluation Act\*](#) is proposed legislation to extend current Medicare telehealth reimbursement waivers through 2024 and commission a study on permanent telehealth flexibility. This bill serves to address inequities that result from living in rural or underserved areas.
- The [\*Metastatic Breast Cancer Access to Care Act\*](#) is again in Congress with two Bills proposed for legislation: [House Bill HR3183](#) and [Senate Bill S1312](#). Passing of this Act would remove the wait-time barriers for receiving Social Security Disability Insurance and access to Medicare
- Urge your representatives to support these legislative efforts. You can find contact information for your Senators and Representatives and by going to <https://www.usa.gov/elected-officials>

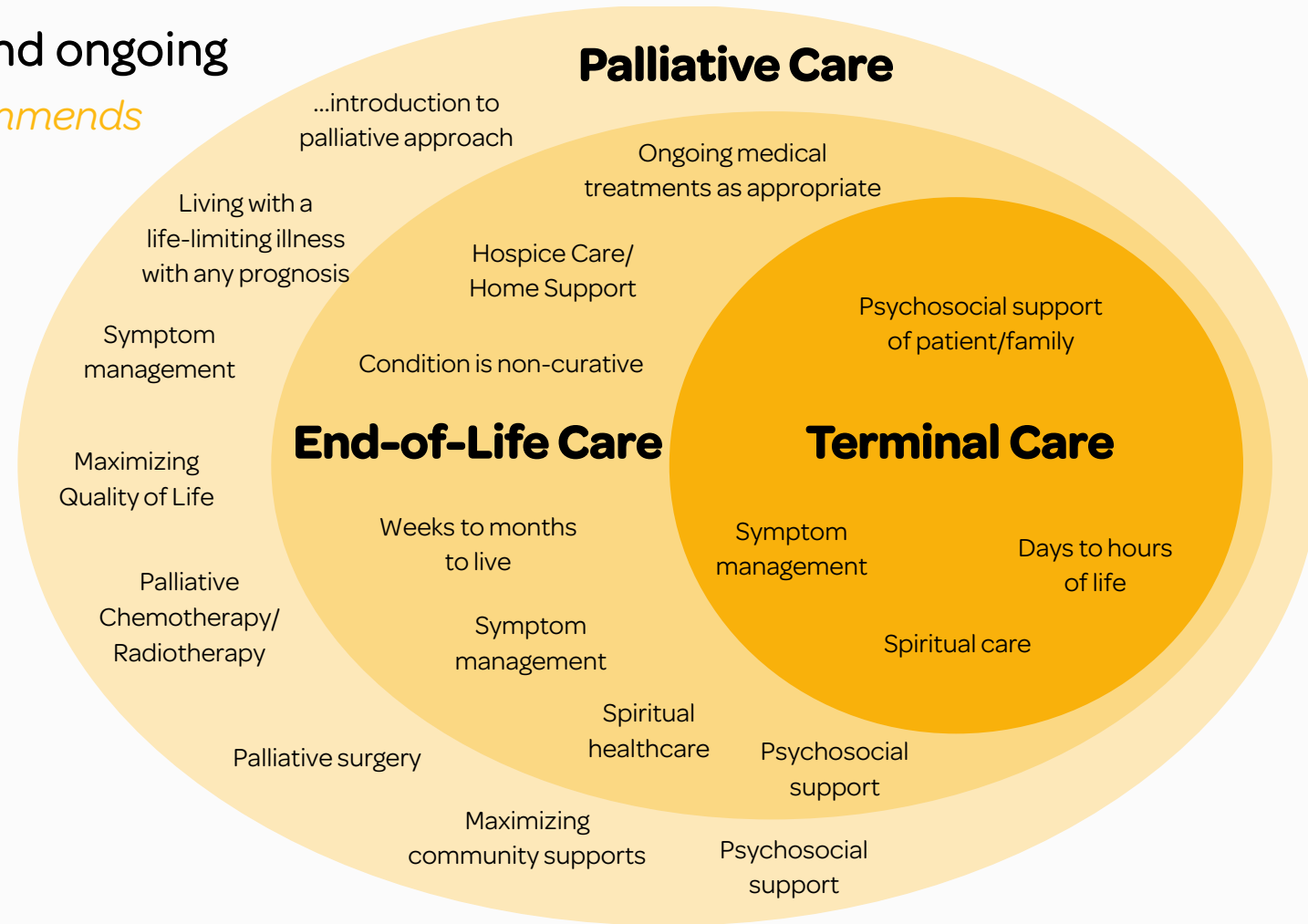
# challenge

## Access to palliative care for MBC

The right time for palliative care is early and ongoing

*The American Society of Clinical Oncology recommends early access to palliative care in MBC*

- Whether called palliative or supportive care, the goal is to support a patient physically, emotionally, spiritually, and socially through
  - Integrative Oncology: Complementary medicine therapies in conjunction with conventional cancer treatments, such as naturopathy, acupuncture, cancer massage, and Reiki
  - Cancer Pain Management: Medications and interventions to manage cancer pain and minimize side effects
  - Cancer Psychiatry/Psychology: Supporting the mental health of cancer patients
  - Cancer Nutrition: Maintaining and optimizing nutrition in cancer patients
  - Cancer Rehabilitation: Preventing and improving physical limitations and function



<https://hpc.providencehealthcare.org/about/what-palliative-care>

Sources: <https://ascopubs.org/doi/full/10.1200/JCO.2018.79.2721>

# Patient Voices



*For me, being a male with breast cancer I felt a little uncomfortable, being diagnosed with a “woman’s disease”... I focus on living. I focus on making plans, for dinner, for vacations, for time spent with family and friends and especially precious time with my wife... [But] be concerned for your children, for your sons & daughters, because breast cancer knows no boundaries and neither do our genes!*

**Kirby**

MBC diagnosis in 2016



*I was diagnosed with Stage II Invasive Ductal carcinoma (IDC) in 2011. My wife and I were devastated. We are fortunate to live in an open and affirming community where our sexual orientation has not created barriers for us or our children. In 2019, when we thought we had put cancer behind us, I was diagnosed with Stage IV Metastatic Breast Cancer. As before our community and healthcare providers welcomed my wife as a core part of my team. Not everyone is as fortunate as we are. I have a friend who has the same diagnosis. They consider themselves to be gender neutral and use “they/them” as their preferred pronouns. Because breast cancer is often thought of as a “female” cancer they have found both the healthcare system and the support group network unwelcoming and at times, downright hostile.*

**Melinda**

MBC diagnosis in 2019



*This is one way stopping fighting cancer empowers: [I choose] lesser opioids more often, extra-strength Tylenol, a steroid for inflammation, cannabis candy in my toolkit. My toolkit to adjust or not.*

**Dorothy** *(in memoriam)*

MBC diagnosis in 2015

THANK YOU >>>  
Questions?



For more information and  
specific sources, visit:  
<https://mbca.me/asd-series3>

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