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# Bridging Researchers and Impacted Communities for Health Equity in Breast Cancer

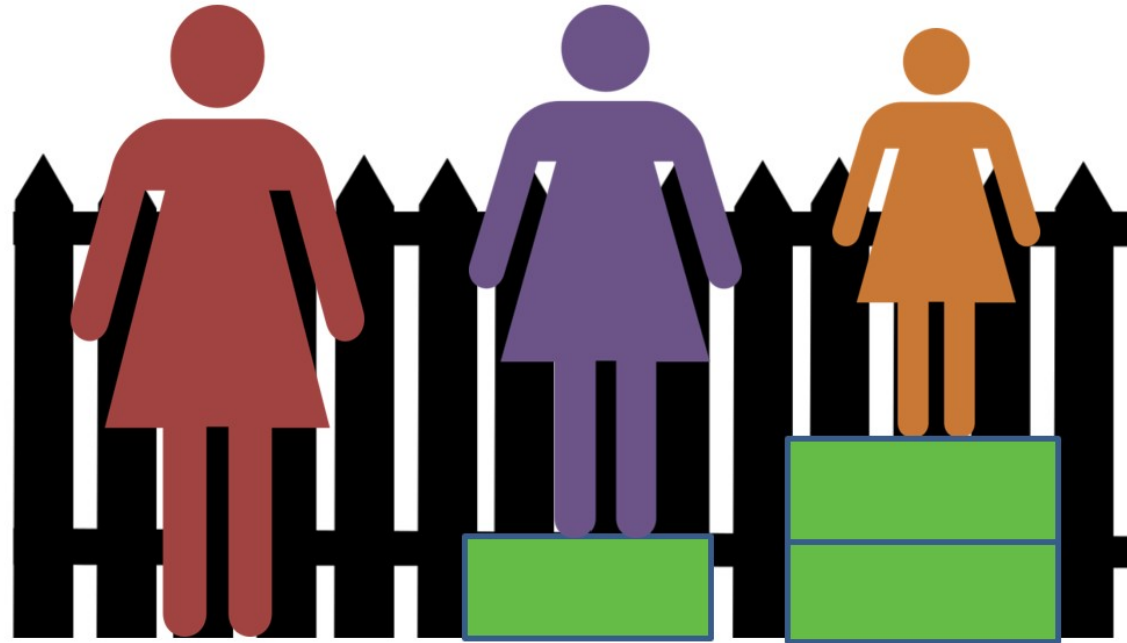
Catherine Thomsen, MPH

Program Director

*January 28, 2021*



# What is health equity?



**EQUITY**

# Community Engaged Research

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- Goals – reflect community needs
- Process – appropriate for participants
- Dissemination

Researchers



Communities





# CYGNET Study Youth Advisors



**CYGNET Study**  
KAISER PERMANENTE

**WHAT TO EXPECT AT CLINIC**



Written by the Youth Advisory Board for CYGNET Participants



So we're in Year 8 of the study... Now What?

## Instructions for Using Your Menstrual Calendar

Please fill out the calendar on the days you are having any vaginal bleeding or symptoms, so it's not hard to remember later. You may want to keep this in your bathroom or near your bed or desk.

If you didn't have any bleeding in the month or you haven't yet started your period, please let us know by checking "Didn't Have a Period" or "Forgot to Fill Out Calendar" on that month.

**FEBRUARY 2013**  Didn't Have a Period  Forgot to Fill Out Calendar

If you get to the end of the month and forgot to fill it out, just check the box "Forgot to Fill Out Calendar" on that month.

**FEBRUARY 2013**  Didn't Have a Period  Forgot to Fill Out Calendar

**Bleeding (Fill Only ONE Circle):** There are 3 ways to describe how much bleeding you have:

- Light** means not much bleeding, maybe not all day or throughout the day or it may even happen on days when you might not expect your period.
- Medium** is for what seems like normal bleeding to you (changing a pad or tampon every 2-4 hours), or if you don't know whether it's heavy or light.
- Heavy** is for lots of blood, so maybe you need to change your pad or tampon every hour or so.

Please fill only **ONE** of the three circles (light, medium, or heavy) that best describes your period each day you had it as shown below:

Correct	Incorrect	Correct	Incorrect
<input type="radio"/> Light <input type="radio"/> Medium <input type="radio"/> Heavy	<input type="radio"/> Light <input type="radio"/> Medium <input checked="" type="radio"/> Heavy	<input type="radio"/> Light <input checked="" type="radio"/> Medium <input type="radio"/> Heavy	<input checked="" type="radio"/> Light <input type="radio"/> Medium <input type="radio"/> Heavy

**Symptoms (Check any that apply, more than one is okay!)** There are two symptoms you should check that describe your period or that might ever happen on the days around bleeding or when you didn't have bleeding.

- Cramps**, which feels like muscle pain or tightness, but in your abdomen or stomach, or also your back and thighs. This may feel like an aching cramp.
- Bloating**, which may feel like you're really full, or a little heavier or have to go to the bathroom.

Once you finish filling out the 2 months on a calendar page, please fold it over, insert in the postage paid reply envelope, seal it, and just drop it in the mail. No one can see what's in them.

Please remember to put the new calendar page in your packet for the next 2 months until both calendars are filled out and mail each whether you had a period, you didn't have a period, or you forgot to fill out the calendar.

For every 2-month calendar page we get back from you, we will send you a \$15 Amazon gift card!

If you have questions, please call the CYGNET Study at 576-891-3884

Thank you for helping us learn about development in girls!

**CYGNET Menstrual Tracking Calendar**

Mail each 2-month calendar as soon as it is completed. Do not wait until the end of the year.

- Please do not write your name or address in the calendar or envelope.
- Just fill the calendar, insert it into the postage paid reply envelope, and seal it like shown in steps.
- Drop the envelope in the mail box. The program already pays for postage.

**FEBRUARY 2013**  Didn't Have a Period  Forgot to Fill Out Calendar

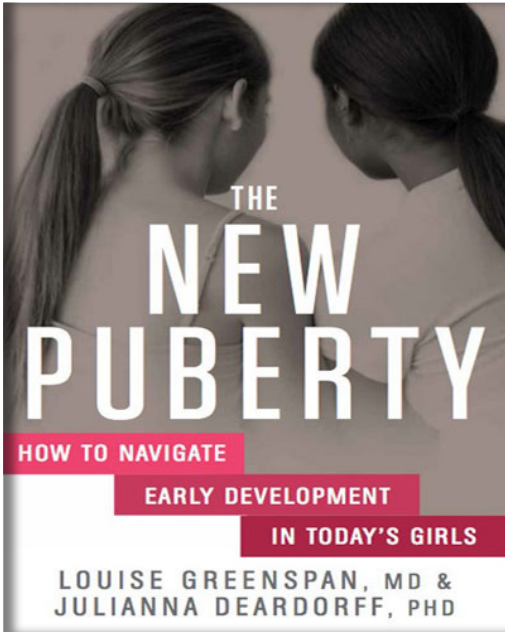
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

**MARCH 2013**  Didn't Have a Period  Forgot to Fill Out Calendar

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				



# CYGNET Youth Advisors to Girls' New Puberty Campaign



**Girls' New Puberty**  
 WHEN **8** YEAR OLD  
 GIRLS HAVE **13**  
 YEAR OLD BODIES

JUST A GENERATION AGO LESS THAN 5% OF ALL GIRLS STARTED PUBERTY BEFORE THE AGE OF 8 (NOW IT'S 10%+)

10% OF GIRLS  
 ...START PUBERTY BY AGE 8

15% OF GIRLS  
 ...START PUBERTY BY AGE 9

25% OF GIRLS  
 ...START PUBERTY BY AGE 10

**Las niñas y la nueva pubertad**  
 CUANDO LAS NIÑAS DE **8** AÑOS TIENEN CUERPOS DE NIÑAS DE **13** AÑOS

LOS CUERPOS DE NUESTRAS NIÑAS COMIENZAN A DESARROLLARSE A UNA EDAD MÁS JOVEN QUE NUNCA, MUCHO ANTES DE LOS 8 AÑOS (AHORA ES MÁS DEL 10%)

10% DE LAS NIÑAS  
 ...COMIENZAN SU PUBERTAD ANTES DE LOS 8 AÑOS

15% DE LAS NIÑAS  
 ...COMIENZAN SU PUBERTAD ANTES DE LOS 9 AÑOS

25% DE LAS NIÑAS  
 ...COMIENZAN SU PUBERTAD ANTES DE LOS 10 AÑOS

**早來的青春期**  
 當 **8** 歲的女孩有 **13** 歲女孩的身軀

我們上一代人只有不到5%的女孩在8歲前開始青春期 (現在已經翻了一倍!)

根據統計  
 10% 的青少年  
 ...都在八歲時踏入青春期

15% 的青少年  
 ...都在九歲時踏入青春期

25% 的青少年  
 ...都在十歲時踏入青春期

WHAT CAN WE DO?    ¿QUÉ PODEMOS HACER?    我們能做什麼?

# Pathways Community Advisors to Survivorship Campaign



## MEMORY & THINKING PROBLEMS AFTER BREAST CANCER

Facts for people who have had breast cancer and those who care for them.



**It is real & you are not alone**

Have you heard the term Chemo Brain? For years, women who had been treated for breast cancer reported memory and thinking problems and were mostly ignored. Finally, more scientists and doctors have come to accept that cancer and cancer treatment can cause such problems.

They are working to understand what is happening and how to help people who have had cancer deal with Chemo Brain, better known as Cancer-related Cognitive Impairment (CRCI). What a relief to know that we don't have dementia. We can take heart, too, that most of us will recover our brain function and that there are things we can do to deal with memory/thinking problems.

**zero**  
breast cancer

Following is the story of Karen, a breast cancer "survivor" who shared her story of CRCI with our Community Advisory Board member, Paula Coombs. Karen lives in Northern California and was diagnosed at age 39, when her 3 children were under 9 years old.



# CHDS Community Advisors to Generations Campaign



*Protecting yourself  
protects future  
generations*

**Use a stainless steel or glass bottle.**  
Drinking from plastic, even BPA-free, exposes you to harmful chemicals.

zero breast cancer | chds Child Health and Development Studies | GENERATIONS Protecting yourself, your children, and their children



Get the facts at [zbclink.org/gen](https://zbclink.org/gen)

# Connect with us!

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Email [info@zerobreastcancer.org](mailto:info@zerobreastcancer.org)

Facebook, Instagram [@zerobreastcancer](#)

Twitter [@zerobreastcancer](#)

[www.zerobreastcancer.org](http://www.zerobreastcancer.org)

[g](#)

zero  
breast cancer

# Today's Speakers

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# Advocacy Opportunities

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## Participate in research

- National Cancer Institute
- Love Research Army
- Local cancer center
- California Breast Cancer Research Program

## Help make/change policy

- National Coalition for Cancer Survivorship
- The Latino Cancer Institute
- Local cancer center

## Volunteer

- Peer to peer support (WCRC, Sharsharet)
- Help with materials (ZBC)

# Thank you co-sponsors!



**Tigerlily**  
**Foundation**  
*Beauty. Strength. Transformation.*



**THE LATINO CANCER INSTITUTE**  
Connect. Convene. Advocate.





**April:** The Role of Our Social and Built Environments in Breast Cancer

**July:** Culture, Language and Addressing Inequities in Breast Cancer

**October:** Environmental Justice for Breast Cancer Prevention

[www.zerobreastcancer.org](http://www.zerobreastcancer.org)

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