Navigating Cancer
&
Making It to Shore

A Survivor Perspective

Mary ("Dicey") Jackson Scroggins
Pinkie Hugs, LLC
International Gynecologic Cancer Society
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pinkiehugs
We care about people, causes, movements. And we document them.

Good Morning!

To Focus Our Efforts…

A Tribute to Patients and Survivors

In remission, in recurrence, in active treatment, and in every conceivable state of personal discomfort and challenge, Cancer Survivors

- **Advocate** for themselves, their families, their friends, their neighbors, and strangers unable to advocate for themselves
- **Educate** health professionals and the general public about cancer prevention, access to care, and treatment and about the everyday personal side of life with and after cancer
- **Participate** in scientific review panels and clinical trials
- **Walk, run, and wheel in chairs** in support of research funding and legislative action
- **Put human faces** and real lives on the disease
- **Advocate and fight** for Equal Access, Quality Care, and the Best Possible Quality of Life for Everyone
- **Choose Hope** even when despair seems so tempting and requires so little
- **Understand that Every Second, Every New Dawn is a Gift, a Blessing *undisguised***

I stand with them, yet in awe of them, and we all stand in their debt.

A Tree Grows Strong in Honor of Cancer Survivors Everywhere

Planted in Kenya on the Masaai Mara on October 17, 2005

Purpose & Objectives

Purpose—To provide a survivor-advocate perspective on navigation of cancer journeys

Objectives

- To enhance cancer literacy with understanding of basic and gynecologic cancer facts and lingo/terminology
- To understand the impact of hereditary breast and ovarian cancer and the significance of genetic testing—to decision-making and care
- To distinguish between options and rights
- To understand clinical trial basics, myths vs realities, and clinical trial association with personalized care
- To spark awareness of the power of advocacy

Walking on Onions—Surviving Ovarian Cancer

- Symptoms Ignored/Misunderstood
- Surgery and Diagnosis (“Good News/Bad News”?)
- Chemotherapy and a Funny Family (*Not forgetting to live while struggling to survive*)
- Love, Well Wishes, Prayers, E-mailed Jokes, Healing Thoughts
- Need for Education and the Company of Survivors
- An Unintended Development—Advocacy/Activism

Organization Building—
In My Sister's Care

- The Decision to Form
- Initial Focus—Ovarian Cancer and African-American Women
- Seven Primary Areas of Concentration
- So **no woman will be alone** in her journey
- The Importance of Partnerships

Keeping the Medically Underserved in the Forefront

- Serving All, Focusing on the Medically Underserved
- Eliminating Barriers to Clinical Trial Participation
- Questioning Access and Care
- Finding and maintaining a Place at the Table
- Building and Sustaining Alliances
- Eliminating Disparities (Simply “reducing” is unacceptable.)

…at the Bedside & in the Community

- "I think standard of care is good, when you can get it."
- "Genetics—that's why I'm tall…and cute."
- "All care is personalized since it's based on my condition/illness."
- "Personalized medicine? *Really?*...I don't think my insurance covers that."

Cancer 101—The Basics

Cancer—A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer. **Carcinoma** is a cancer that begins in the skin or in tissues that line or cover internal organs. **Sarcoma** is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. **Leukemia** is a cancer that starts in blood-forming tissue, such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood. **Lymphoma and multiple myeloma** are cancers that begin in the cells of the immune system. **Central nervous system cancers** are cancers that begin in the tissues of the brain and spinal cord. Also called malignancy.

NCI Dictionary of Cancer Terms (https://www.cancer.gov/publications/dictionaries/cancer-terms)

Cancer 101—The Basics (continued)

Basic Terminology

- An abnormal mass of cells is a **tumor**.
- **Benign tumors** are not cancer; **malignant tumors** are cancer.
- When cancer cells break away from the original (primary) tumor, travel through the blood or lymph system, and form a new tumor in other organs or tissues of the body, it is called **metastasis** (that is, the spread of cancer cells from the place where they first formed to another part of the body). The new, metastatic tumor is the same type of cancer as the primary tumor.
- **Stage** is the extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body.

Cancer 101—The Basics (continued)

Basic Terminology (continued)

- In cancer, **grade** is a description of a tumor based on how abnormal the cancer cells and tissue look under a microscope and how quickly the cancer cells are likely to grow and spread. Low-grade cancer cells look more like normal cells and tend to grow and spread more slowly than high-grade cancer cells. Grading systems are different for each type of cancer. They are used to help plan treatment and determine prognosis. Also called histologic grade and tumor grade.
- Cancer that has **recurred** (come back), usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body. Also called recurrent cancer.
- **Prognosis** is the likely outcome or course of a disease; the chance of recovery or recurrence.
- A **gynecologic oncologist** is a doctor who has special training in diagnosing and treating cancers of the female reproductive organs.
- …

Cancer 101—The Basics (continued)

Gynecologic Cancers 101

- **Common Gynecologic Cancers**—What are the most common gynecologic cancers?
  - ☐ See “Women’s Cancers” on International Gynecologic Cancer Society website: www.https://igcs.org/about/womens-cancers/
- **Symptoms**—What symptoms should you investigate?
- **Diagnosis**—What tests are available?
- **Points to Remember**—Of what should you be mindful?

Show—https://sparkmedia.org/projects/what-every-woman-should-know/

Cervical Cancer

- **Symptoms** (in more advanced form)
  - Abnormal bleeding, spotting, or vaginal discharge
  - Bleeding after intercourse
  - Pain during intercourse
- **Tests**
  - Pap Test (*Annual*)
  - HPV Test (Ask your gynecologist if right for you.)
- **Points to Remember**
  - An HPV vaccine can protect against many types of HPV that cause cervical cancer and genital warts.
  - Routine Pap Tests are important throughout life, even if you have received the HPV vaccine.
  - Most people who have HPV have no symptoms and can transmit it unknowingly to others.
  - Condoms can help prevent transmission of the virus but are not 100% effective.

HPV Vaccine Uptake in Australia

HPV vaccination coverage differs by sex

- In 2017, 80.2% of females and 75.9% of males aged 15 years had received all 3 doses of the HPV vaccine.

Uptake of HPV vaccinations in females has increased

- The uptake of all 3 doses among females aged 15 years increased from 71.9% in 2012 to 80.2% in 2017.

Uptake of HPV vaccinations in males has increased

- The uptake of all 3 doses among males aged 15 years increased from 62.4% in 2014 to 75.9% in 2017.

HPV vaccination coverage is lower in very remote areas and those of lower socioeconomic status

- In 2014, the proportion of males or females aged 12-13 years who had received all 3 doses was lower in Very Remote areas than in other remoteness areas, and lower in low SES areas than in higher SES areas.

National Cancer Control Indicators, https://ncci.canceraustralia.gov.au/prevention/hpv-vaccination-uptake/hpv-vaccination-uptake

Ovarian Cancer

- **Symptoms**
  - Persistent Bloating
  - Recurring pelvic or abdominal pain
  - Difficulty eating or feeling full very quickly
  - Frequent urination or immediate need to urinate
  - Other persistent symptoms, including fatigue, indigestion, back pain, pain with intercourse, and constipation.
- **Tests**
  - There is no specific test for ovarian cancer.
  - Women with symptoms should ask for a series of tests, including
    - Vaginal-Rectal Pelvic Exam
    - CA125 Blood Test
    - Transvaginal Ultrasound or other imaging test
- **Points to Remember**
  - The Pap Test does not detect ovarian cancer.
  - Women often have the vague symptoms of ovarian cancer at the earliest stage, when the cancer is more “curable.”
  - Symptoms that come and go frequently or that last for 2 or more weeks should not be ignored.

Uterine/Endometrial Cancer

- **Symptoms**
  - ☐ Vaginal discharge or abnormal vaginal bleeding (that is, irregular bleeding between periods prior to menopause or spotting after menopause)
  - ☐ Pain during urination and/or intercourse
  - ☐ Two or more weeks of persistent pain in the lower abdomen or pelvic region
  - ☐ Watery pink or white vaginal discharge
- **Tests**
  - ☐ There is no specific test for uterine cancer.
  - ☐ Annual vaginal-rectal pelvic exam is recommended.
  - ☐ Ask your gynecologist or a gynecologic oncologist about an endometrial biopsy.
- **Point to Remember**
  - ☐ If you have *any* abnormal or irregular bleeding or any vaginal discharge, talk to a doctor.

Cancer Lingo,
On the Road to Health Literacy

- More than words, for example,
  - **Adjuvant Therapy**—Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy. (Usually surgery followed by other therapy)
  - **Neoadjuvant Therapy**—Treatment given as a first step to shrink a tumor before the main treatment, which is usually surgery, is given. Examples of neoadjuvant therapy include chemotherapy, radiation therapy, and hormone therapy. (Usually surgery follows other therapy)
- Dictionaries
- Glossaries
- **Health Literacy**—Health literacy supports consistent high-quality care and joint decision making—more than knowing terms, includes understanding systems and the ability to meaningfully advocate for survivor-patient benefit.

What's in a Word or Two: Terminology

Myth vs Reality

- Placebo
- Randomization
- Comorbidities
- Guinea Pig
- No Other Treatment Options/Last Resort

Clinical Trial Myth vs Reality

Myth	Reality
The Tuskegee Syphilis Study is “the” reason for low enrollment of African Americans and perhaps other vulnerable populations.	The Tuskegee Syphilis Study or what it represents is “a” reason—that is, one among many others—not “the” reason. In fact, it can become an excuse—an easy “out”—for the opportunity to participate not being offered.
African-American and Hispanic patients are less likely to participate in clinical trials than Whites are.	Although both former groups are less likely to be invited to participate in trials, when asked, they are slightly more likely to enroll. (Wendler et al, PLoS Medicine, 2006)
Trial participants are <u>guinea pigs</u> and may be experimented on in ways beyond their consent.	There are numerous regulations and safeguards that ensure that human participants are protected and that research is ethical, including 45CFR46. All US research including human participants is reviewed and monitored by an Institutional Review Board (IRB), whose focus is their protection.
Clinical trials are or should be an option only when potential participants have <u>no other treatment options</u>.	Clinical trial participation can and should be an option for any patient who meets specific trial eligibility requirements and wants to participate. Not all patients will choose to participate, but all should be given the option to do so when appropriate.
Some clinical trial participants will receive treatment that is inferior to standard of care, perhaps through <u>randomization</u> and/or <u>placebo</u> use.	All clinical trial participants will receive at least standard of care. “Randomization” and “placebo” strike fear in the hearts of potential participants. This fear can be educated away.

Patient Protection and Research Ethics

US History of Research Ethics

Littered with but not defined by infamous events such as

- Tuskegee Syphilis Study (1932-1972)
- Nazi Experiments
- Willowbrook Studies (1956-1972)—Children deliberately infected with hepatitis virus
- Jewish Chronic Disease Hospital Studies (1963)—Chronically ill and debilitated patients infected with live cancer cells
- Henry Beecher’s Article in New England Journal of Medicine (1966)—“Ethics and Clinical Research,” focus on informed consent and ethical investigators [not an infamous event]
- AIDS Clinical Trials (1980’s)

Adapted from slides of Steven Joffe, MD, MPH

Codes of Research Ethics

Nuremberg Code (1947)

- Informed consent, societal value, unacceptable levels of risk

Declaration of Helsinki (orig. 1964)

- Written protocol, independent review

Belmont Report (1979)—outlines basic ethical principles in research involving humans

- Added justice, fair "subject" selection

Adapted from slides of Steven Joffe, MD, MPH

Criteria for Ethical Research

- Social Value
- Scientific Validity
- **Fair "Subject" Selection (better known as "Patients" or "Participants")**
- Reasonable Balance of Risks and Benefits
- Independent Review
- **Informed Consent**
- Respect for Enrolled "Subjects"

Emanuel et al. JAMA 283: 2701

Informed Consent

- What is Informed Consent? Why is it necessary?
- What is it intended to provide?
- What must it include? How long should it be—in length and time?
- How should it be conducted? By whom?
- What should be considered/promoted in the absence of a formal “consenting” tradition or process?

(Remember who it should protect.)

Informed Consent—The Document

- Introduction—Initial explanation/invitation/ask
- Statement that the study involves research/Purpose Statement
- Statement that participation is voluntary
- Description of study (will be enhanced by visual protocol schema)
- Approximate number of study participants
- Description of risks
- Description of benefits
- Disclosure of appropriate alternatives
- Confidentiality Statement (to include handling of identifiable personal information)
- Cost-related information (to include costs participant or insurance company might have to cover, such as treatment of injury)
- Termination and withdrawal information
- Handling of significant findings
- Contact name and information for questions/concerns

(Informed Consent is not just a document; it is also a process.)

Adapted from 45CFR46.116(a)&(b)

Clinical Trial Participation is a powerful form of [Research] Advocacy!

Personalized Medicine/Care— The Great Promise of

The Delivery of

The Right Treatment,

to the Right Patient,

at the Right Time

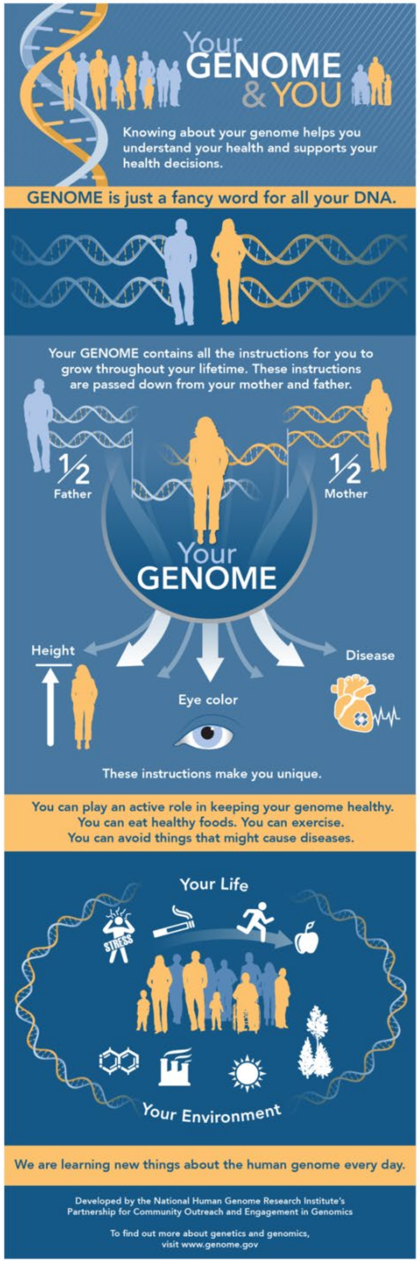
Personalized Medicine/Health Care—a form of **medicine that uses information about a person's genes, proteins, and environment** to prevent, diagnose, and treat disease

…& A Daunting Challenge

- **Race as the first filter** (reliance on this “marker”)
  - Only one of a list of factors
  - Supports de facto acceptance of cause and casualties
  - Uneven outcomes as long as the outcomes are primarily confined to certain populations, zipcodes/neighborhoods, regions, and classes
- **Social Determinants of Access and Care**
  - Personalized medicine and cancer health disparities closely track with social determinants, socioeconomics, and sociodemographics
  - Environmental conditions, stressors, place/type of work, educational level, income, etc—surrogates for likelihood of health care equity
- **Engagement in the Clinical Trial System and State of Care**
  - A robust clinical trial system yields greater opportunity for participation in and benefit from it.
  - Participation increases likelihood of having “skin in the game.”
  - Limited or uneven access has the opposite effect.

Genetic, Genomics, Linked Stuff that Doesn't Start with "Ge"

- **Genetics**—Testing/Counseling/Treatment
- **Hereditary Breast & Ovarian Cancer Syndrome (HBOC)**—https://www.facingourrisk.org
- Knowing your **BRCA Status**—Why?
- **Genomics**
- **Personalized Medicine**—Health care & Clinical Trial engagement—biospecimen banking—as a gateway mechanism.



Knowing about your genome helps you understand your health and supports your health decisions.

GENOME is just a fancy word for all your DNA.

Your GENOME contains all the instructions for you to grow throughout your lifetime. These instructions are passed down from your mother and father.

These instructions make you unique.

You can play an active role in keeping your genome healthy. You can eat healthy foods. You can exercise. You can avoid things that might cause diseases.

We are learning new things about the human genome every day.

Developed by the National Human Genome Research Institute's Partnership for Community Outreach and Engagement in Genomics

To find out more about genetics and genomics, visit www.genome.gov

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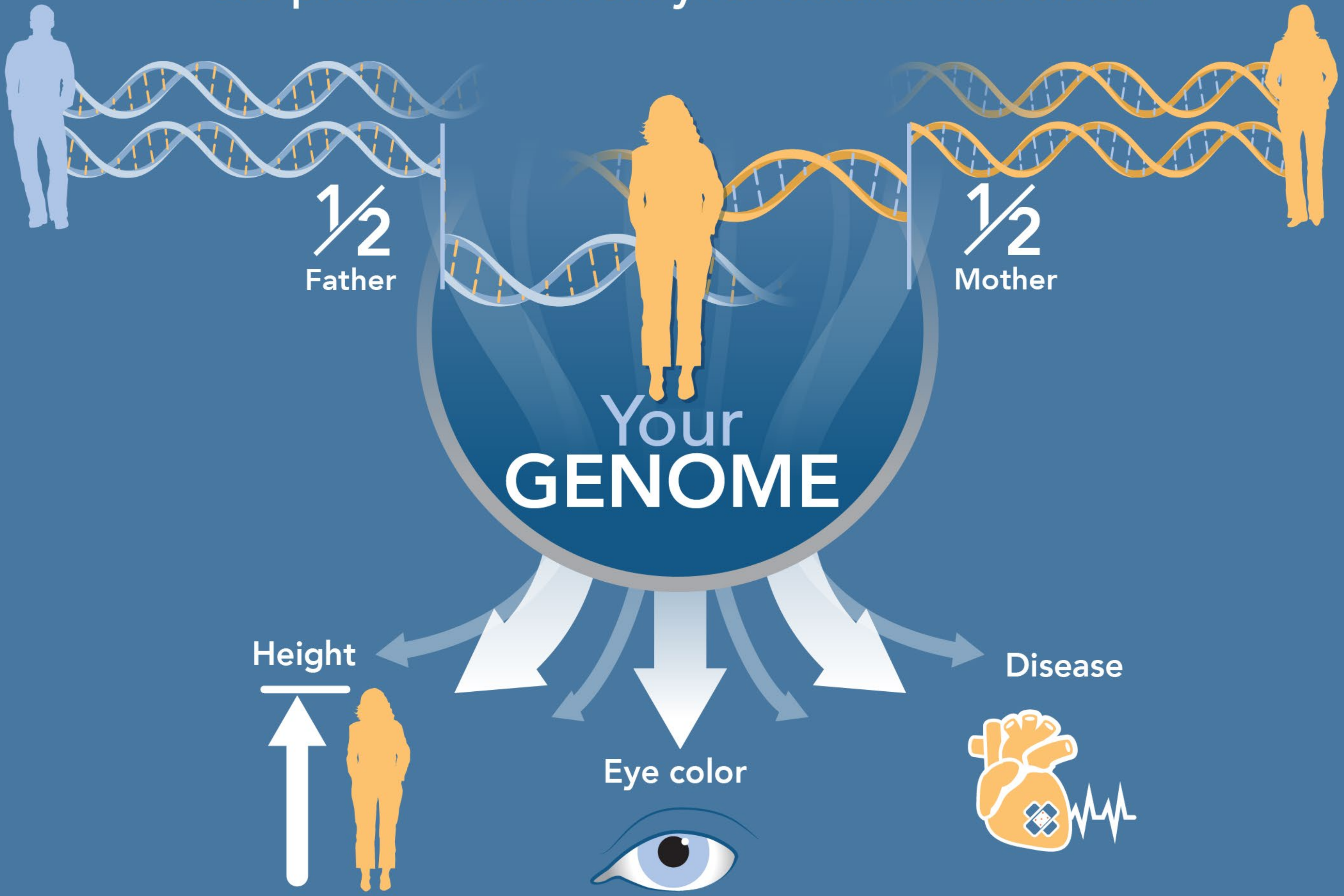

½
Father

½
Mother

Your
GENOME

Height

Eye color

Disease

These instructions make you unique.


50% MOMMY
50% DADDY
100%
AMAZING!

You can play an active role in keeping your genome healthy.
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Knowing Your Options/Rights

- **Appointment preparation** and toolkit (knowing what to ask/what to bring)
- Understanding **care/treatment options**, including specialist care (differs locally/regionally/internationally)
  - ❑ For example, Why chose a gynecologic oncologist?
- The right to **genetic testing/the necessity for genetic counseling**
- **Sharing medical history** as an act of family unity/love
- Authentic treatment-related **shared decision-making** (a level of health literacy as a precursor)
- **Palliative Care**—A regular part of general care—neither optional nor simply end-of-life specific

Knowing Your Options/Rights (continued)

- Getting a **Second Opinion**, for initial care and recurrence(s)
- Incorporating **Complementary and Alternative Medicine**/Techniques
- **Patient-Reported Outcomes (PROs)**/Quality of Life Assessments—reported directly from the patient, unfiltered and unedited
  - ☐ Where/Why assessed?
  - ☐ To what purpose?

Globe-athon Pass It On

Globe athon

To End Women's Cancers

In Summary…

- Survivors do not need to be scientists, but they do need to have **basic cancer literacy**, as a matter of survival and survivorship and to navigate this journey.
- Understanding **cancer lingo/terminology** enhances our ability to access standard of care and to engage in shared decision making.
- **Clinical trials** are "care" and advocacy options and are gateway mechanisms for personalized medicine/care.
- Patient **rights include palliative care** as a part of the continuum of care.
- **PROs** should be embedded in health policy and in health care instructions and options.

The journey is uncertain but navigable.

We can make it to shore, thriving all the way.

An Example of

The Power of Collective Action and Networking

An HIV/AIDS Women's Collective in a Kenyan Village that supports members through basket weaving and educates others through plays

Nothing is beyond the reach of a group of dedicated, passionate people…anywhere and under any circumstance on the planet

Greetings from Three Little Advocates-in-Training

Acknowledgments/Resources

- Anwar Perry, Sanaa Perry, and Asha Perry (my grandchildren), My Little Advocates-in-Training
- AACR Scientist↔Survivor Program—assembles advocates from around the world to network, enhance skills, and engage researchers during AACR Annual Meeting
- American Society of Clinical Oncology (ASCO), www.asco.org
- Center for Global Health, National Cancer Institute, www.cancer.gov/aboutnci/globalhealth
- Foundation for Women's Cancer, https://www.foundationforwomenscancer.org/
- International Gynecologic Cancer Society, www.igcs.org
- National Cancer Institute, www.cancer.gov
- Steven Joffe, MD, MPH
- Survivors Teaching Students: Saving Women's Lives^{SM} Program of the Ovarian Cancer National Alliance—trains survivors to teach medical students and other health care professionals about ovarian cancer (can be applied to other cancers)

And always, thanks to Alice Beers, my first oncology nurse.

Additional Acknowledgments

- Survivors/Patients, Family Members, Caregivers
- Community Voices
- Strangers unable to advocate for themselves
- Clinicians, Researchers, Other Health Professionals
- Untold hours in discourse on the topic

Akiba, Darlene, Thelma, Lawton, Gwen, Mildred, Jackie, Zora, Bettye, Joe, LaShawn, Heather, Jerry, the Man in the brown striped suit, Cindy, Johnny, Annie, the Woman alone in Shreveport, Nyrvah, Marcia, Ann, Bo, the Taxi Driver's Aunt, both Jims, …

Thank You!

And, Pinkie Hugs!

(An intertwining of baby fingers—pinkies—by two people as a symbol of affection and caring)

“Pinkie Hugging” Instructions

1. Make a soft fist.
2. Extend your pinkie (baby finger).
3. Stretch your pinkie. No tension, please. (Tension is a pinkie hug spoiler.)
4. Wiggle your pinkie to attract/invite another pinkie.
5. Extend your pinkie toward receptive other pinkie. (Don’t be shy, but not too aggressive.)
6. Reach out and embrace the receptive other pinkie, locking fingers in a firm but gentle hug.

Pinkie hugging is addictive and confers a promise, a commitment. So, pinkie hug selectively. We do.

Courtesy of Pinkie Hugs, LLC