Highlights from the 2018 Joining FORCEs Against Hereditary Cancer Conference

Finding and participating in clinical trials
Sue Friedman, Executive Director and Founder, FORCE

Why participate in research? Everything we know about prevention and treatment comes from research, yet only 3% of adult cancer patients participate in clinical trials. One study of over 500 National Cancer Institute trials showed that 40% of them did not achieve enrollment goals. This leads to incomplete studies and jeopardizes collecting and publishing data that could have otherwise added to our understanding of cancer.

Myths about research participation:
- Research is only for last resort treatment options.
- You will be denied treatment or good care.
- If an attending physician doesn’t refer a patient to a clinical trial, there must not be one.

Facts about research participation:
- Every clinical trial has strict safety measures.
- Placebos are only included in studies in which there is no standard of care or treatment.
- Doctors may not be aware of, or refer patients to studies outside of their own facilities.

Some studies are specifically for individuals with hereditary cancer syndromes. These people are uniquely qualified for studies that can provide new insights on treatment, prevention, and quality-of-life for individuals with hereditary cancers.

Do you qualify for a study focused on hereditary cancer?
If you want to participate in research, you can! The FORCE research study tool, with patient-friendly trial summaries and descriptions of study inclusion criteria, can match you to a study that fits your interests. Use FORCE’s Research Study Tool to find the tool and link to other resources. [http://www.facingourrisk.org/research-clinical-trials/studies-enrolling-patients/index.php](http://www.facingourrisk.org/research-clinical-trials/studies-enrolling-patients/index.php)

The following are ongoing or soon to be open research studies presented in this session. If you are interested in any of these, please use the provided links and/or email addresses to get more information.
City of Hope: Victoria Seewaldt, MD

- Study to determine whether Metformin prevents breast cancer in premenopausal women who are at high risk for breast cancer (with study sites across the country).

- Study to improve imaging by utilizing the natural florescence in hemoglobins (a protein that transports oxygen in the blood) to image breast vasculature. One goal of this study, which hopefully will be enrolling by the next FORCE conference, is to find a high-resolution imaging alternative to breast MRI.
  
  www.cityofhope.org
  vseewaldt@coh.org

Cedars-Sinai, Rudy Cornejo

- At least 50 current studies at Cedars-Sinai relate to breast cancer.
  
  https://www.cedars-sinai.org/programs/cancer/trials.html

- HealthCare Outcomes after Risk Reducing Oophorectomy focuses on understanding the impact of surgical menopause on cognitive function, bone health, cardiovascular disease, and quality of life. Female mutation carriers who are planning risk-reducing bilateral salpingo-oophorectomy are eligible.
  

- The Gilda Radner Hereditary Cancer Program is a study designed to identify factors that influence cancer risk and to better understand the precursors to cancer so that preventive steps can be employed for individuals with and without inherited genetic mutations.
  
  https://cancertrialinfo.csmc.edu/adultcancersprotocols.php?protocol_no=1080&cancertype=Breast

UCLA, Wendy Conlin, CGC

- Hundreds of cancer-related trials are ongoing at the Jonsson Comprehensive Cancer Center.
  
  https://cancer.ucla.edu/patient-care/enroll-in-a-clinical-trial/find-a-ucla-clinical-trial

- Research Study for Young Women Survivors of Breast Cancer aims to identify and care for the needs of women after completing treatment.
  
  https://cancer.ucla.edu/patient-care/enroll-in-a-clinical-trial/find-a-ucla-clinical-trial?id=2098
  
  Barbara Kahmills
  bkahmills@mednet.ucla.edu

UC San Diego Health, Moores Cancer Center, Suzanna Lee, MD and Hailey Tipton, MPH

- 150-190 trials are open and enrolling trials at a given time.
• The Wisdom Study will determine whether or not personalized mammogram screening timelines are more effective.
• I-Predict involves tumor testing for all cancer types to understand the genetic markers of the range of unique breast tumors, and to consider and match drugs based on the profile of a patient’s tumor. The goal is to understand personalized care for cancer.
  cancercto@ucsd.edu

**USC Norris Comprehensive Center, Anson Snow, MD**
• Are there alternative ways to treatment?
• Do diet and exercise improve cancer progression?
• Hereditary cancer studies (several groups).
• The multi-center I-SPY 2 study is tailoring several arms of therapy based on genetic markers in each patient’s metastatic breast cancer.
• The HOMING study strives to understand the basic biology of circulating tumor cells that have broken away from the tumor and are detectable in blood.
  http://Cancer.keckmedicine.org/patients/clinical-trials/