



# Cancer Genetics Network

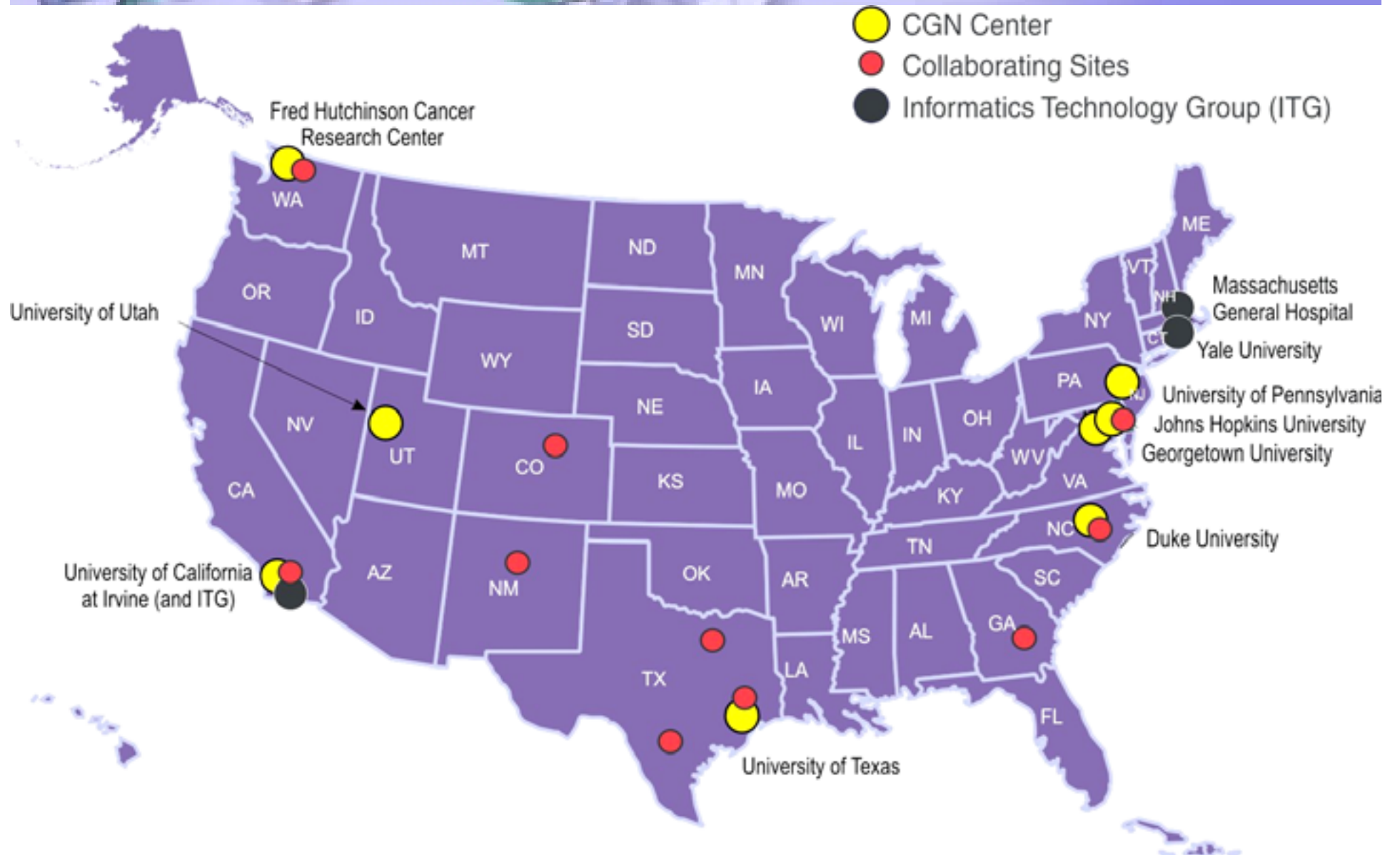
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## The Cancer Genetics Network Is...

... an NCI-sponsored research infrastructure comprising a multi-site registry of persons with cancer or at high risk of cancer and their families for investigations on the genetics of cancer and other related issues





## Steering Committee

- PIs of each of the 8 Participating (enrolling) Centers, 3 Informatics Centers, Advocates, NCI Program Director, and Special Experts
- Main governing board; sets CGN scientific directions, and future goals
- Develops and ensures streamlined access to CGN resources for research purposes



# Advisory Committee

- Senior scientists with broad expertise in cancer genetics research
- Advisory to the Steering Committee
- Reviews pilot study protocol
- Sets performance guidelines for the Participating Centers and the Information Technology Group

## Working Groups

- Thirteen Working Groups composed of experts from among the PIs, Co-PIs, their staff, and NCI staff
- Currently most active are Behavioral Science, Education and Communication, Biospecimens and Laboratory, and Minority Recruitment



# Informatics Technology Group

Designs, implements, and maintains the information management systems that support multi-center CGN-wide research:

- Coordinating Center for CGN activities
- Recruitment Pool core data
- Web-accessible clinical data management system software for specific studies



# Two-Stage Participation

## **Entry into the CGN Recruitment Pool**

- Identified through population-based cancer registry, clinic, or referred by MD and consent obtained
- Completion of the core questionnaires on cancer history, sociodemographic characteristics, etc.

## **Participation in Specific CGN Studies**

- Eligibility determined from for a specific study from core data
- Invited to participate in the specific study; enrolled if consent



## Examples of CGN Pilot Studies

- *Methodologic* - Biostatistical analysis of cancer prediction models to develop a more accurate algorithm for predicting breast cancer risk
- *Gene discovery* – Genetic and environmental modifiers of penetrance of BRCA1 and BRCA2 mutations
- *Translational* – Ovarian cancer screening using the Risk of Ovarian Cancer Algorithm



## CGN Accomplishments

- 20,202 probands enrolled in the recruitment pool, representing 15,163 families – March, 2003
- 10 pilot studies underway
- Collaboration with other NCI resources (SPORES, EDRN, SPNs, CFRs, SEER), Cooperative Clinical Trials Groups, and intramural /extramural investigators
- 61 articles published or in press directly using CGN resources



## Services to Investigators

- Collect 4-generation cancer family history pedigrees from enrollees, their families, and other individuals
- Assemble information for and complete medical extraction forms
- Obtain pathology reports and tumor blocks for molecular testing or to verify diagnosis
- Collect biospecimens with desired medical and demographic information for shipping and storing



## Services to Investigators (Cont.)

- Conduct telephone interviews with enrollees
- Recruit patients from high-risk clinics and tumor registries
- Provide genetic counseling
- Contact enrollees' treating physicians prior to enrollment
- Develop software, including computerized follow-up for the study



## CGN Summary

- Well-established, cohesive infrastructure
- Large and increasing recruitment pool
- Used as a resource for investigator-initiated RPG Pool studies
- Partnerships with other NCI supported research infrastructures



## The CGN and the SPNs

- Shared locations, shared sites
- Commitment to specific needs of culturally diverse groups regarding clinical genetics
- Strong support for minority representation in clinical research
- Expertise in public and patient education, community outreach, recruitment/retention



## CGN/SPN Shared Sites

- **Baltimore, MD**  
CGN: Johns Hopkins  
SPN: U Maryland
- **Atlanta, GA**  
CGN: Emory  
SPN: Morehouse
- **Irvine, CA**  
CGN/SPN: UCI
- **Houston, TX**  
CGN/SPN: Baylor
- **Philadelphia, PA**  
CGN: U Pennsylvania  
SPN: Temple, Thomas Jefferson
- **Washington, DC**  
CGN: Georgetown  
SPN: Washington Hospital Center
- **Denver, CO**  
CGN/SPN: U Colorado



## CGN/SPN Collaborations: Redes En Accion

- July 2000: **Discussions on CGN/SPN collaboration initiated at first SPN meeting**
- September 2002: **First Community Consultation on Responsible Collection and Use of Samples for Genetic Research**
- November 2000: **CGN Workshop on Community and International Perspectives on Cancer Genetics Collaborative Research**



## CGN/SPN Collaborations: Redes En Accion (Cont.)

- **April 2001: Working Group Conference on the development of a National Hispanic Community Consultation on Genetic Research**
- ***Redes En Accion* chosen to facilitate a National Latino Genetic Community Consultation, with support from NCI, NIGMS, NHGRI**
- **June 2003: Hispanic/Latino Genetics Community Consultation Network summit meeting to identify priority genetic issues**



## SUMMARY

- Concerns of diverse populations about the use of genetic information are of major importance in today's science and its applications in health care.
- CGN and SPNs share commitments to recognize and address the concerns of these groups and to support their participation in clinical research.
- CGN/SPN collaborations can be particularly successful in achieving common goals.