

# **MINORITY FAMILIES BREAST CANCER FAMILY REGISTRY RESOURCES AND ON-GOING RESEARCH**

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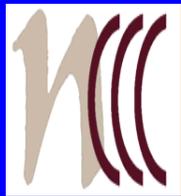


# RACIAL/ETHNIC DISPARITIES IN BREAST CANCER

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- **Pronounced racial/ethnic disparities in breast cancer incidence, clinical presentation at diagnosis, survival, and mortality**
- **Minorities are generally under-represented in observational and intervention studies of breast cancer.**
- **Reasons for disparities are not well understood.**
- **The BCFR has established an infrastructure and assembled resources and expertise to facilitate such research focused on minorities.**

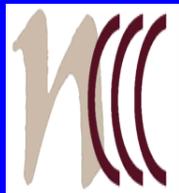


## MINORITY FAMILIES IN BCFR

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- The BCFR has a unique collection of minority families.
- Of 12,655 families enrolled, 3,838 are minority, accounting for 30%.
- These minority families represent a broad range of breast cancer risk
  - 61% of minority families are population-based, mostly recruited in California
  - 39% are clinic-based, mostly recruited in New York and Philadelphia registries



# MINORITY FAMILIES IN BCFR

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	1995-2005 N=12,655	2006-2010 N=950 (proposed)
Non Ashkenazi Whites	6,763	
Ashkenazi	1,688	
Minorities	3,838	
Hispanic	1,107	530
African-American	896	420
Asian-American	1,565	
Other	270	
Unknown	366	



# ON-GOING RESEARCH ON MINORITY FAMILIES

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- On-going studies at California site
  - Racial/ethnic differences in enrollment
  - Racial/ethnic differences in accuracy of self-reported family history
  - *BRCA1* and *BRCA2* in minorities
- Funded collaborative studies



# MINORITY FAMILIES IN NORTHERN CALIFORNIA FAMILY REGISTRY

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- Population-based registry in SF Bay area
- Cases ascertained through the NCI-funded SEER cancer registry
- Ethnically diverse population
- Two stage-sampling design
  - Over-sample cases at increased genetic risk for breast cancer
  - Over-sample **minority** families
- Bi-cultural, bi-lingual interviewers
- In-person interviews to build rapport



# PROBAND RECRUITMENT PROTOCOL

## CANCER REGISTRY

21,023 incident cases

→ 86.7% eligible for screening

4.2% Deceased  
1.0% MD refusal  
8.1% Can't locate

## SCREENING by telephone

16,286 90% → 3,242 eligible

9.0% Refusal  
0.6% Language  
0.6% Other

## FAMILY HISTORY by telephone

## EPIDEMIOLOGY by in-person interview

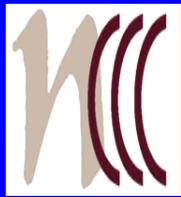
2,433 78%

18% Refusal  
3.0% Lost  
0.8% Other

## BIOSPECIMENS at in-person interview

2,120 70%

25% Refusal  
5% Other



# PROBAND PARTICIPATION

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	Screening N=16,286	Epid Quest 2,433	Biospec 2,120
<b>All</b>	<b>90%</b>	<b>78%</b>	<b>70%</b>
<b>Whites</b>	<b>91%</b>	<b>83%</b>	<b>77%</b>
<b>African-Americans</b>	<b>91%</b>	<b>82%</b>	<b>77%</b>
<b>Hispanics</b>	<b>92%</b>	<b>76%</b>	<b>73%</b>
<b>Filipinas</b>	<b>90%</b>	<b>68%</b>	<b>52%</b>
<b>Chinese</b>	<b>87%</b>	<b>74%</b>	<b>54%</b>
<b>Japanese</b>	<b>86%</b>	<b>74%</b>	<b>66%</b>
<b>Other</b>	<b>74%</b>	<b>86%</b>	<b>75%</b>



# RELATIVE RECRUITMENT PROTOCOL

**PROBAND CONSENT** to contact relatives  
(sisters, parents, adult daughters)  
**90%**

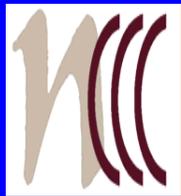
**10%** No proband  
consent to contact  
any relatives

**7,800** relatives considered for biospec  
**41%** relatives contacted  
  
**2,270** **75%** gave **BIOSPECIMEN**

**34%** Deceased  
**14%** No prob consent  
**11%** Outside USA

**5,531** relatives considered for epid quest  
**43%** relatives contacted  
  
**1,860** **82%** completed **EPI QUEST**

**27%** Deceased  
**17%** No prob consent  
**13%** Outside USA



# ACCESS RELATIVES

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	# 1 <sup>st</sup> degree relatives	Overall refusal (proband)	Individual refusal (relatives) N=7,800	Foreign residence (relatives) N=7,800
<b>All</b>	<b>3.9</b>	<b>10%</b>	<b>22%</b>	<b>16%</b>
<b>Whites</b>	<b>3.4</b>	<b>6%</b>	<b>13%</b>	<b>4%</b>
<b>Afr-Am</b>	<b>4.3</b>	<b>6%</b>	<b>33%</b>	<b>2%</b>
<b>Hispanics</b>	<b>3.8</b>	<b>4%</b>	<b>20%</b>	<b>27%</b>
<b>Filipinas</b>	<b>3.9</b>	<b>17%</b>	<b>24%</b>	<b>31%</b>
<b>Chinese</b>	<b>3.6</b>	<b>23%</b>	<b>30%</b>	<b>25%</b>
<b>Japanese</b>	<b>4.6</b>	<b>12%</b>	<b>16%</b>	<b>20%</b>
<b>Other</b>	<b>4.1</b>	<b>17%</b>	<b>19%</b>	<b>29%</b>



# RELATIVE PARTICIPATION

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	Epid Quest N=1,860	Biospec N=2,270
<b>All</b>	<b>82%</b>	<b>75%</b>
<b>Whites</b>	<b>89%</b>	<b>81%</b>
<b>African-Americans</b>	<b>82%</b>	<b>74%</b>
<b>Hispanics</b>	<b>82%</b>	<b>75%</b>
<b>Filipinas</b>	<b>73%</b>	<b>63%</b>
<b>Chinese</b>	<b>71%</b>	<b>60%</b>
<b>Japanese</b>	<b>82%</b>	<b>74%</b>
<b>Other</b>	<b>79%</b>	<b>75%</b>

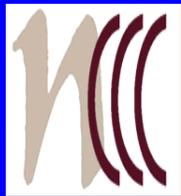


## **SUMMARY**

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- **Family studies in minority populations are more challenging due to greater proband refusal to contact relatives, and more relatives residing outside of the US.**
- **Relative participation is similar to that of probands**
- **Analyses are on-going to assess participation by family history, age, and other characteristics, and racial/ethnic differences in reasons for non-participation**

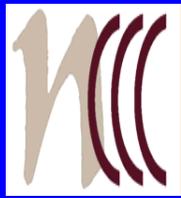


# **RACIAL/ETHNIC DIFFERENCES IN ACCURACY OF FAMILY HISTORY**

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- **Re-entered family history data by proband**
- **Compare proband report to relative self-report**
  - **Analyses based 2,098 first-degree relatives**
  - **Estimated sensitivity (%SE) & positive predictive value (%PPV) of breast cancer reporting by proband**
  - **Used Generalized Estimating Equations (GEE) to adjust for inclusion of multiple relatives per family**

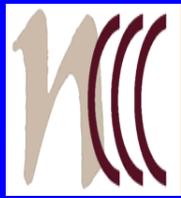


# ACCURACY OF PROBAND REPORTING: BREAST CANCER

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	Probands	Relatives	%SE	%PPV
Whites	430	746	95.7	99.4
African-Americans	219	447	90.7	97.5
US-born Hispanics	116	249	90.6	89.4
Foreign-born Hispanics	93	183	90.0	100.0
Chinese	92	165	90.5	100.0
Filipina	90	173	100.0	100.0
Japanese	40	63	100.0	100.0
Other	33	72	100.0	100.0

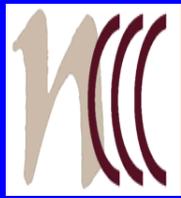


# **BRCA1 AND BRCA2 MUTATIONS IN MINORITIES**

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- Completed *BRCA* testing in 1,200 minority probands from Northern California site
- Identified 35 *BRCA1* and 37 *BRCA2* mutation carriers
- On-going analyses:
  - To estimate population-based **prevalence** of *BRCA1* and *BRCA2* mutations among African-American, Hispanic, Chinese, and Filipina probands.
  - To describe the **spectrum** of *BRCA1* and *BRCA2* mutations in these populations.
  - To evaluate **BRCAPRO** in minorities.



# **COLLABORATIVE RESEARCH PROJECTS FOCUSING ON MINORITIES**

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- **Genetics and Breast Cancer in Blacks**  
PI: Funmi Olopade, R01  
*Compare blacks from Nigeria to African-Americans in Northern California registry*
  
- **IGF Pathway and Breast Cancer in African-Americans**  
PI: Susan Neuhausen, BCRP  
*African-Americans in Northern California registry and Multi-ethnic case-control study*

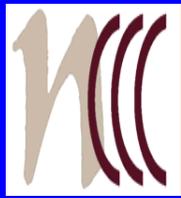


# COLLABORATIVE RESEARCH PROJECTS FOCUSING ON MINORITIES

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- **Admixture and Breast Cancer in Latinas**  
PI: Elad Ziv, DOD  
*Latinas in Northern California registry and  
Multi-ethnic case-control study*
- **Pilot Study on Ethno-cultural Differences in  
Cancer Risk Beliefs and Behaviors**  
PI: Mary Daly  
*Minorities from 6 sites*

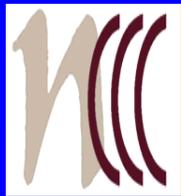


## CONCLUSIONS

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- A broad range of BCFR studies focused on minorities are on-going or planned.
- Unique contributions by BCFR studies
- NCI's Investment in Cancer Research in 2006:
  - Etiologic studies targeted to US minority groups, including **Hispanic** and **African-American** populations.
  - Studies of populations in transition, such as populations from Asian and **migrant populations** in the US.
- The BCFR infrastructure building and research agenda of the Minority Platform are directly responsive to NCI's priorities.



# PARTICIPATION IN BCFR VS CASE-CONTROL STUDY

	Epidemiology Questionnaire		Biospecimens	
	BCFR	C-C	BCFR	C-C
<b>Breast cancer cases Aged 35-64 yrs</b>				
<b>Whites</b>	<b>82%</b>	<b>90%</b>	<b>77%</b>	<b>79%</b>
<b>Hispanics</b>	<b>76%</b>	<b>92%</b>	<b>73%</b>	<b>78%</b>
<b>African-Americans</b>	<b>83%</b>	<b>89%</b>	<b>77%</b>	<b>82%</b>