

Breast Cancer and Breast Health Education and Research among Deaf and Hard of Hearing (D/HH) Women



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The Deaf/HH Community

- 8-10% of all Americans
- 30 million persons nationwide
- 1 in 10 can't hear or understand normal speech



The Deaf/HH Community

- Heterogeneous population
 - Demographic characteristics
 - Age, race, socioeconomic status, etc.
 - Age of onset
 - Degree of hearing loss
 - Language usage
 - ASL, Signed English, etc.
 - Identification with Deaf Culture & deaf community
 - A unique cultural, social, educational minority community
 - Shaped by history of segregation, prejudice & discrimination



The Deaf/HH Community

- Frequently poor
- Low literacy levels
 - Adults on average read at 3rd/4th grade level
- Inadequate communication with physicians
- Poor preventative health behaviors
- Lower levels of health knowledge
- Fears from incomplete and incorrect information
- Limited access to services and resources



Why this study?

- A unique cultural and linguistic population
- Barriers to breast health/breast cancer
- Knowledge and participation in breast health advocacy
- Need for programming for deaf and hard of hearing women with little education
- Need for research to develop programs



Overall Study Goals

- To develop, test & disseminate a tailored breast cancer control educational intervention for women who are D/HH
 - Focus on poor & underserved populations
 - Reduce barriers to breast health for D/HH
 - Gain knowledge useful in addressing barriers faced by other underserved low literacy minority groups



Building on Previous Research

- **Breast Health**
Advocate Illinois Masonic Behavioral Health Services (Chicago)
- **Every Deaf and Hard of Hearing Woman Counts!**
Breast Cancer Education
University of California San Diego, Moores Cancer Center
- **UCLA/GLAD Pilot Research**
 - Funded by the California Breast Cancer Research Program
 - In depth interviews with 68 D/HH women
 - Identified gaps in knowledge, incomplete mammography screening
 - 41.9% in prior year for women with high school or less education
 - Lack of participation in breast cancer advocacy
 - Communication barriers



Overall Approach

- Build on pilot study findings
- Serve all D/HH women
 - General population and breast cancer survivors
- Community/academic partnership
- Community commitment & involvement
 - GLAD leadership
 - Community Advisory Committee
 - Partner agencies throughout Southern California
- Funded by Susan G. Komen Breast Cancer Foundation & California Breast Cancer Research Program



Elements of Research

- Demonstration

- 40 women, 40+ years old, racial/ethnic diversity, including 20 breast cancer survivors
- Pilot test for RCT
- Outcome: change in knowledge and attitudes
 - Assessment at baseline, post-intervention, 6 month follow-up

- Randomized Controlled Trial

- 200 women, 40+ years old, racial/ethnic diversity
- Outcome: differences in intervention/control condition
 - Primary/secondary prevention, knowledge & attitudes
 - Breast health advocacy and communication
 - Assessment at baseline (pre/post program), 12 month follow-up)



Program Name

SIGNS OF AWARENESS:
A Visual Guide to Breast Cancer
for the Deaf/Hard of Hearing



Intervention

- Used in demonstration & RCT
- Small group format led by trained deaf health educator, use of visual aids
- Tailored written materials with emphasis on visual, limited English language usage
 - Supplemented by standard brochures



Intervention

- Tailored DVD
 - Modular elements and sidebars
 - ASL, limited written captions, voice over
 - Animation: emphasis on visual content
 - Narration by deaf actress
 - Content delivered by deaf medical doctor



Intervention (Con't)

- Participation of D/HH survivors & community members
- Signed, voice-over, captioning
- Comprehensive breast health content
 - Risk factors, primary prevention, secondary prevention, diagnosis, treatment, survivorship
- Focus on overcoming communication barriers
- Encouragement of breast health advocacy
- Provision of resources





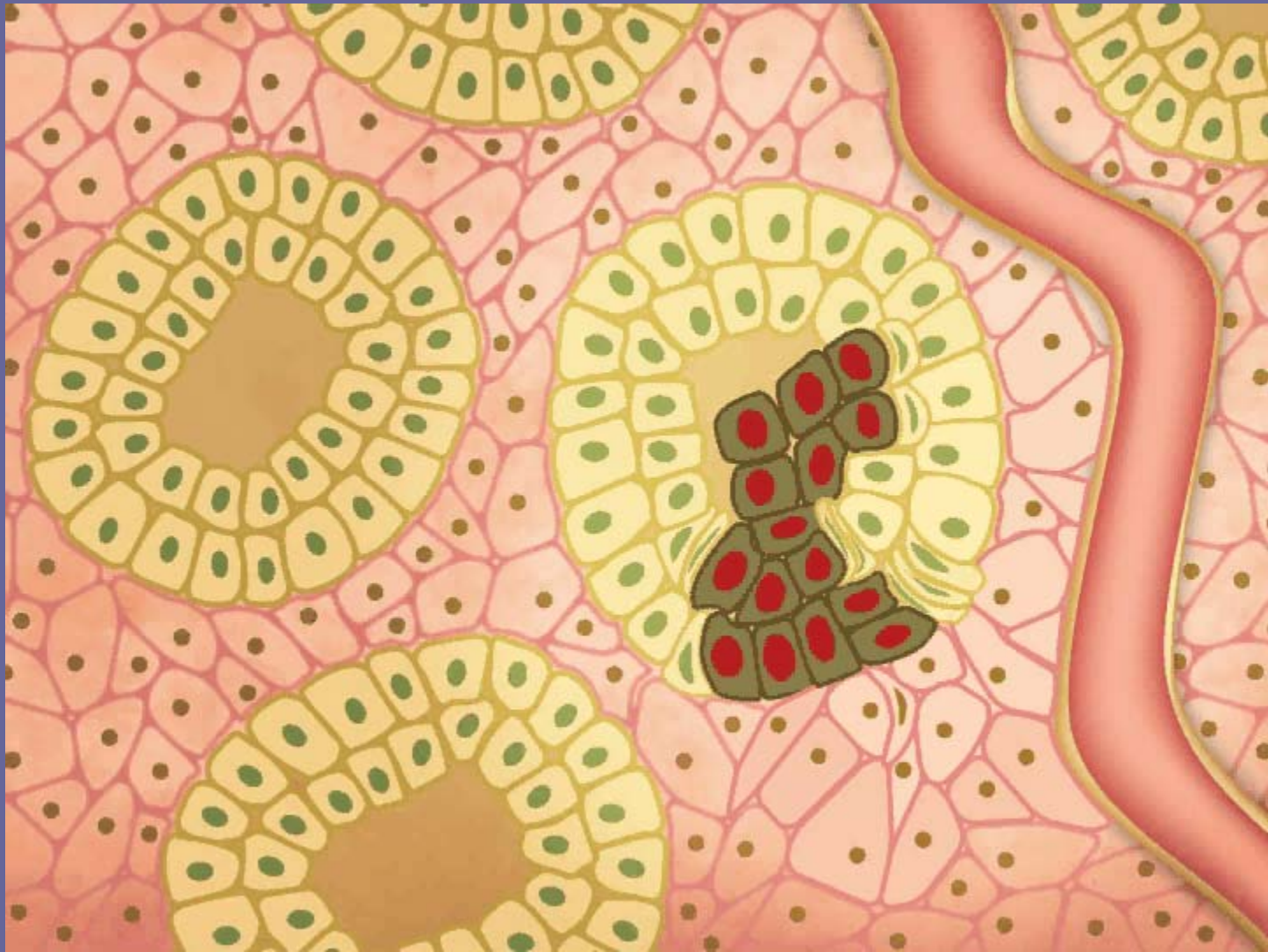


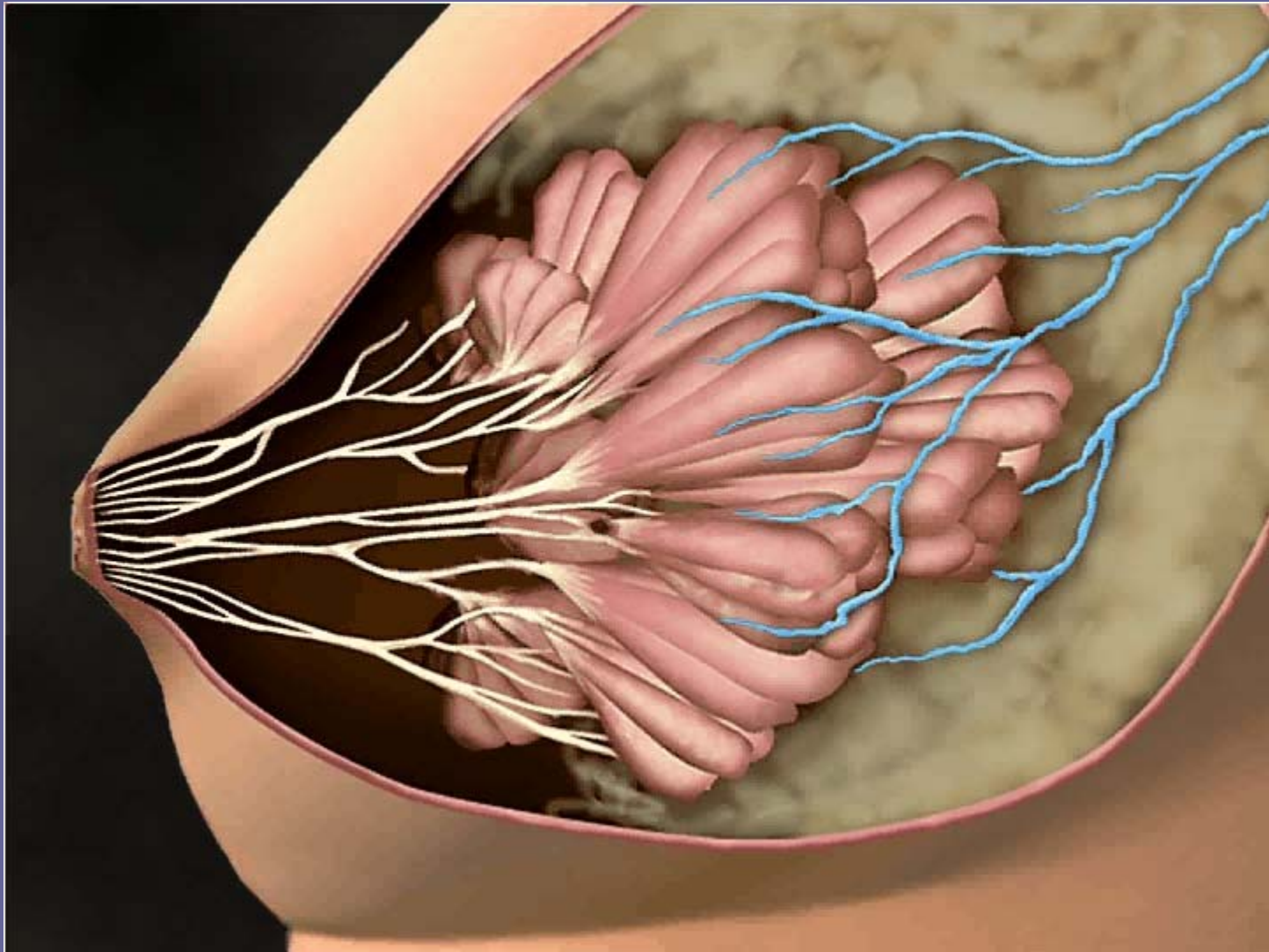


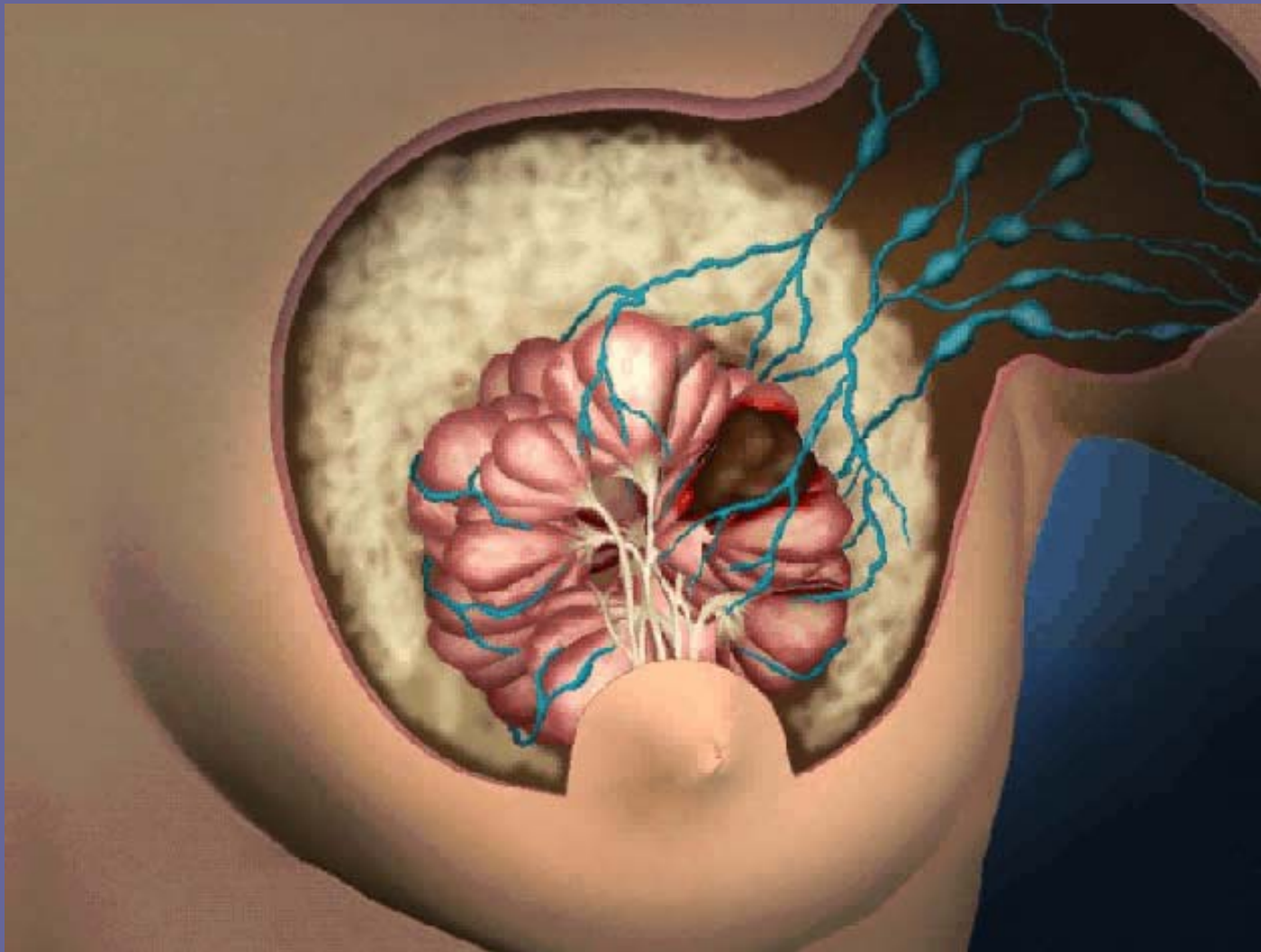












Control Group

- Small group format
- Commitment to programming by research team & funding agency
- Cancer Prevention for women
 - Focus on lifestyle: nutrition, exercise, tobacco use & sun safety
- PowerPoint presentation
- Supplemental brochures - ACS



Data Collection

- Surveys for use at baseline
 - Pre-program delivery
 - Post delivery
 - Follow-up
- Use of multiple strategies for follow-up
 - In person, TTY, E-mail, video phone (VP)



Research Challenges

- Creating comprehensive, understandable content
 - Tailored to Deaf/HH women with lower levels of formal education
- Translating written materials to simplified English & ASL
- Developing visual images to capture complex concepts
- Alternating presentations and visual aids
 - Simultaneous communication not feasible
- Crafting survey instruments that capture complex concepts
 - Translating to ASL & presenting in written format



The Research Team

- **Greater Los Angeles Agency on Deafness, Inc. (GLAD)**
 - Heidi B. Kleiger, B.S., PI (Community)
 - Alicia Wolfson, B.A.
- **UCLA Division of Cancer Prevention and Control Research, School of Public Health and Jonsson Comprehensive Cancer Center**
 - Barbara A. Berman, Ph.D., PI (Academic)
 - Roshan Bastrani, Ph.D., Co-I
 - Angela Jo, M.D., MSHS, Co-I
 - William G. Cumberland, Ph.D., Statistician
- **Community Advisory Committee**
 - 5 Deaf/HH community members
 - 3 are breast cancer survivors
 - Racial/ethnic, age & socio-economic diversity
- **Consultants**
 - Gary Kaufman, M.D., Mt. Sinai Health Systems Deaf Access Program, Chicago, Illinois
 - Georgia Robins-Sadler, Ph.D., University of California, San Diego
 - Carolyn R. Stern, M.D. Rochester, NY
 - Philip Zazove, M.D., University of Michigan health Systems

