### ARCHIVING THE RANCHO BERNARDO STUDY OF HEALTHY AGING

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# **Rancho Bernardo Study: The Beginning**

 Founded in 1972 by Elizabeth Barrett-Connor, MD, as part of the nation-wide Lipid Research Clinic (LRC) Prevalence Study



Original RBS "Trailer Clinic"



Dr. Barrett-Connor

### Rancho Bernardo Study: The 1st Year

- 6339 participants, ages 30 to 79.
- 82% of Rancho Bernardo residents aged
  30 and older









### Rancho Bernardo Study: The Next 44 Years



### **Rancho Bernardo Study: The Cognitive Function Cohort**



94% Follow-up for Vital Status

Additional long-term assessments: CVD, diabetes, bone health, physical function, psychosocial well-being, health-related behaviors, mortality

## **Rancho Bernardo Study: The Data**

#### **Selected Variables Available**

#### Demographic, lifestyle and health data available at 5 or more RBS clinic visits

Marital status, living arrangement	Disease history - personal, family	Body size & composition
Hormone use, reproductive history	Physical function tests –	Height, weight, waist & hip girth
Quality of life (SF12)	Grip strength, chair stand, gait	Body fat, lean body mass (DXA)
Health status (SF36)	Dietary intake	Clinical chemistries
Depressed mood (BDI)	Tobacco habit	Blood pressure: SBP, DBP
Self-assessed health status	Alcohol use	Total, HDL, LDL cholesterol
Hospitalizations, doctor visits	Physical activity, limitations	Triglycerides
Validated medications	ECG, angina, claudication	Fasting glucose
Biological measures available at 1 to 3 RBS clinic visits		
Hearing / Vision	Vitamin D, PTH	IGF1, IGFBP1
Arthritis (by exam)	Fasting & post-challenge	Adipocytokines
ApoE genotype	Insulin, glucose	Leptin, adiponectin, ghrelin
Subclinical CVD measures	HbA1c	Sex hormones, SHBG
Carotid IMT	Proinsulin, C-peptide	Testosterone, estradiol, estrone
Coronary artery calcium	Endothelin-1, LpPLA-2	Adrenal hormones
Peripheral arterial disease	Inflammatory markers	Cortisol, DHEA, DHEAS
Lipoprotein subclasses	IL-6, hsCRP, fetuin-A	Trace minerals
Psychosocial measures available from clinic visits and/or yearly mailers		
Standardized Questionnaires	Perceived Stress Score	Pfeffer Functional Activities Q'n
Emotions	Life Satisfaction Index-Z	Economic Decision Making
Stress	Satisfaction with Life Scale	Self-assessed Numeracy
Hostility	Pittsburg Sleep Quality Inventory	BEM Sex Role Inventory
Social contact	Inventory Activities of Daily Living	Female Sexual Function Index
Optimism, Pessimism	Fatigue Scale	Male Sexual Function Inventory

## Rancho Bernardo Study Reports ..... the early years



Risk of heart attack is 2 times higher in nonsmoking women married to smoking men (1984).

A high potassium diet (4-5 servings of fruit and vegetables/day) reduces stroke risk. A high sodium, low potassium diet increases blood pressure. (1987,88).





Women have more social connections than men, and social networks predict longevity (1990).



## Rancho Bernardo Study Reports ..... the early years



Moderate alcohol intake, exercise, not smoking and losing weight are all associated with higher HDL cholesterol levels ---- the "good" cholesterol





People who eat 3 to 4 meals per day have better lipid levels than those who eat the same number of calories in 1 or 2 meals

### **Rancho Bernardo Study Current Focus**



NIAAA R01 AA021187 Associations of diet and alcohol with late life brain health and cognitive function.

### Rancho Bernardo Study: Scientific and Educational Contributions



### Rancho Bernardo Study: An International Resource

Inclusion in national and international collaborative analyses:

- Endogenous Hormones and Breast Cancer Collaborative Group (University of Oxford)
- Emerging Risk Factor Collaboration (University of Cambridge)
- Prospective Studies Collaboration (University of Oxford)
- Chronic Kidney Disease Prognosis Consortium (Johns Hopkins)

The invitations and data requests from individual investigators keep coming...

#### **Rancho Bernardo Study: Data Access**





# The RBS Archiving Project: Goals

- Documentation and electronic archiving of the 45 years of RBS data using modern cloud-based methods
- Resource sharing and data dissemination -provision of deidentified data in an open web-based environment to the research community
- Continued follow-up of participants for morbidity and mortality during the archiving process

# **The RBS Archiving Project: Goals**

Critically important and time-sensitive. Data are vulnerable to loss due to lapses in funding and/or retirement of key personnel with loss of essential institutional memory.

Our overall goal is to assure that the scientific community continues to benefit from NIH's long investment in this unique, irreplaceable research resource.

## **Building the Archive Step by Step**

#### **Data Inventory**

All data collection instruments, laboratory reports, and clinical scans will be inventoried and catalogued

#### **Data Harmonization**

Data will be grouped into meaningful categories and standardized across time points

#### **Data Documentation**

Information pertaining to the provenance of all data will be thoroughly documented

#### Data Dissemination

Research IT consultation and services Claire Mizumoto, UC San Diego Research IT

## **Data Dissemination**

#### **Secure Environment Creation**

Established Amazon RDS - HIPAA compliant SQL server Vicky Rowley, UC San Diego Center for Research in Biological Systems

**Relational Database Creation** 

Jit Bhattacharya, Xpertech Solutions, Inc



#### **Website Creation**



KNIT - UC San Diego Digital Commons Cyd Schilling-Burrows, UC San Diego Research IT

## **Rancho Bernardo Study: The Future**

- Our archiving and data sharing project will ensure the continued availability of this unique resource for our students and investigators.
- Continued inclusion in national and international collaborative analyses.
- Use of RBS data in combination with other large cohort studies for big-data approaches, maximizing NIH's long investment in RBS.

# **The RBS Archiving Team**



Elizabeth Barrett-Connor, MD Family Medicine and Public Health 44 years



Gail A Laughlin, PhD Family Medicine and Public Health 20 years



Donna Kritz-Silverstein, PhD Family Medicine and Public Health 31 years



Jaclyn Bergstrom, MS Family Medicine and Public Health 13 years



Linda K McEvoy, PhD Radiology, FMPH 8 years



Ricki Bettencourt, MS Family Medicine and Public Health 20 years

## **Past to Present**



1972



Today

## **Questions?**