

ANNUAL REPORT

2005-2006

RESOURCE FOR GENETIC & EPIDEMIOLOGIC RESEARCH (RGE)

Jean E. Wylie
Director

July 1, 2005 - June 30, 2006

EXECUTIVE SUMMARY

2005-2006 marked the 30th anniversary of the UPDB, saw the move of RGE to the new Research Administration Building, recorded another increase in the net number of projects - from 57 to 64 - and observed an increase in the net number of projects using the GenMed file from 11 to 17.

ORGANIZATIONAL ACTIVITY

OFFICE OF THE VICE PRESIDENT FOR RESEARCH

Vice President for Research

In August, 2005, the Vice President for Research moved most of the research administration offices, including RGE, to a new building on the Health Sciences Campus of the University. The new address is 75 South 2000 East, Salt Lake City, Utah, 84112-8930.

Utah The Vice President for Research continues to provide \$50,000/year towards support of the Population Database through the Pedigree and Population Resource (the RGE computer agent) of the Huntsman Cancer Institute at the University.

RGE Review Committee

Members of the RGE Review Committee for 2005-2006 are listed in Appendix A.

There were no changes to RGE Policies and Procedures in 2005-2006.

DATA CONTRIBUTORS

Cancer Data Registry of Idaho

All requests to use CDRI data are reviewed by the Cancer Analysis Working Group prior to access.

Church of Jesus Christ of Latter-day Saints

Glen Buckner continues to serve as the Church's representative for RGE.

Data Resource Center, University of Utah Health Sciences Center

Cheri Hunter continues to serve as the representative to the Committee from the Data Resource Center.

Driver License Division, Utah Department of Public Safety

Mr. Randy Campbell continues to serve as the DLD reviewer for requests to access DLD data within UPDB.

Huntsman Cancer Institute

Dr. Mary Beckerle continues to serve as the HCI representative to the RGE Review Committee.

Utah Cancer Registry

Dr. Antoinette (Nan) Stroup continues to serve as the UCR representative to the RGE Review Committee.

Utah Department of Health

RGE Review Committee

Dr. Barry Nangle, now Director of the Utah Center for Health Data, which contains the Office of Vital Records and Statistics, continues to serve as the Department's reviewer for requests to access its data through RGE.

OTHER ORGANIZATIONS

The George S. and Dolores Dore Eccles Foundation

Under the auspices of the Huntsman Cancer Institute, the Foundation funded a gala celebration of the 30th anniversary of UPDB on October 9th, 2005. The honorees were the three founders of the database: Lee Bean, Mark Skolnick, and Roger Williams. Professor Bean's contributions were described by Geri Mineau; tribute to Dr. Skolnick was paid by Lisa Cannon-Albright, and the late Dr. Williams' accomplishments were described by Steve Hunt.

The gala was attended by past and current users of the database, by representatives of the data contributors, by senior members of University administration, and by many who had provided staff support over the past 30 years.

In addition to the gala, three days of seminars highlighting the research made available by resources such as UPDB were presented.

The first, a symposium on October 25th, was held in conjunction with the 2005 American Society of Human Genetics meeting in Salt Lake City. The subject of the symposium was “Advances in Human Genetics via Databases of Linked Familial and Medical Records.”

Presenters and attendees were welcomed by both Dr. Stephen Prescott, Director, Huntsman Cancer Institute, and Governor John H. Huntsman, Jr. The morning sessions featured University of Utah researchers, many of whom use the UPDB for their research. The afternoon sessions spotlighted similar research by investigators from around the country. It ended with a discussion of future research in this area, led by Dr Prescott, and Dr. Francis Collins, Director, National Genome Research Institute, National Institutes of Health.

The second seminar, held on October 31st and November 1st, was a seminar on “Kinship and Demographic Behavior”. Presenters at this conference came from around the world to present and discuss kinship and demography both current and historical. In addition to the academic activities, attendees were able to take a private tour of the Family History Library of the Utah Genealogical Society.

The Huntsman Cancer Institute at the University of Utah

Pedigree and Population Resource

The Huntsman Cancer Institute (HCI) continues to underwrite the Pedigree and Population Resource (PPR) as a core resource of the HCI. PPR manages the data within the UPDB, provides consultation to present and future users of the data, and adds to and improves the data. HCI underwrites the computer hardware, security, backup and overall resource management costs for PPR.

High Risk Cancer Clinics

RGE continues to provide an external review, through the RGE Review Committee, of all proposals to use data/resources from the HCI High Risk Cancer Clinics.

Vice President for Health Sciences

In conjunction with the Vice President for Research, the Vice President for Health Sciences has agreed to provide \$50,000/year in on-going institutional support of UPDB.

UPDB: DEVELOPMENT, MANAGEMENT, AND IMPROVEMENT

UPDB IN 2005-2006

From data contributors, this dynamic database receives **annual updates** for births, marriages, divorces, deaths, cancer records, and driver licenses in Utah. A copy of the Ancestral File from the Church of Jesus Christ of Latter-day Saints is available to UPDB; genealogies can be added or updated as needed. There are 8.9 million records in the UPDB and those records include names and other information for family members. Multiple records for an individual are matched to create a “person-oriented record.” From the over 15.8 million individuals named in these records, 6.4 million unique individuals have been created. The longitudinally linked data are able to capture many events associated with an individual.

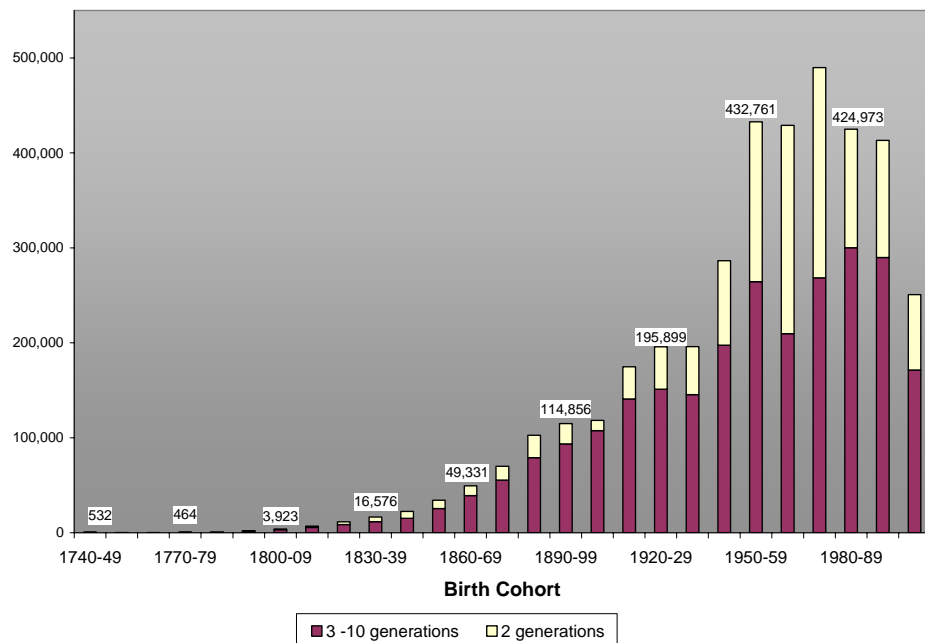
Records Type	Records
Genealogy	1.6 million
Utah Birth certificates (1915-21, 1947-2003)	2.09 million
Utah Marriage certificates (1978-2002)	545,000
Utah Divorce records (1978-2002)	239,000
Utah Death certificates (1904-2003)	694,000
Utah Fetal deaths	6,000
Utah Cancer Registry	216,000
Cancer Data Registry of Idaho	124,000
Driver License Division	2.77 million
1880 Utah Territorial Census	143,000
Social Security Death Index	479,000
Total Records	8.9 million

Geo-coding is now available in UPDB. The Driver License Division has provided a file of information on 5.94 million current and previous addresses for almost 2.8 million individuals. These addresses have been geo-coded using the Universal Transverse Mercator system. Location information includes Easting, Northing, and the 2000 Census tract and block. These data will allow researchers to examine environmental factors and clustering of individuals by geographical location. Research funding for this project was a seed grant from the University of Utah, Institute for Public and International Affairs.

Most families living in Utah are represented in the UPDB. Merging data from genealogy records of the Utah pioneers and their descendants with those from birth certificates allows information for new generations to be added to existing families. Birth and marriage records from UDOH are also used to “reconstitute” Utah families that are not part of the genealogies. The UPDB includes demographic information for more than six million individuals and family history data for almost four million

individuals, representing pedigrees than span up to ten generations. For example, 432,761 individuals born from 1950-59 are in multi-generation families with 168,267 in two generation families and 264,494 in three to ten generations families.

Figure: Individuals (3.84 million) in UPDB, in families of two to ten generations by 10-year birth cohorts from about 1740 to 2004.



A key research value of UPDB is linking the family history data to other files that contain information on disease and health-related conditions.

1. We continue to annually update and link cancer diagnosis in UPDB from the Utah Cancer Registry and the Cancer Data Registry of Idaho. Researchers use these data to study the familial incidence of cancer by identifying and studying families that have a higher than normal incidence of cancer, thereby identifying specific genetic mutations.

2. Beginning in 2003, a collaborative project (GenMed) began developing research information for investigators studying the familiarity of common diseases. This project establishes a **Master Subject Index** of non-identifying, numeric ID numbers (a link) between the medical information contained in the University of Utah Health Sciences Center Data Resource Center (UUHSC), Enterprise Data Resource Center, and the family history information in the UPDB. The UUHSC contains over 1.5 million patient demographic records and over 1 million (70 percent) have been matched to a “person record” in UPDB. This research resource has proven to be highly valuable for many investigators.

3. A new project approved in March 2006 involves the **Utah Birth Defects Network (UBDN)**. The UBDN is the birth defect registry for the state of Utah; it began collecting data in 1994 and includes all

Utah residents born with major structural birth defects. Information on 7,578 individuals has been added and linked to records in UPDB. These data will be used to identify pedigrees that appear to have an excess of birth defects and will be the basis of future familial studies. Over 93% of children linked to records in UPDB and 99.8% had one or both parents that linked. Preliminary analysis showed over 70% had one or more grandparent in UPDB which highlights importance of ongoing development of the family history.

Inclusion of project data sets allows collaborative studies. The UPDB has also been linked to other databases with research significance: the population of the Cache County (Utah) Study of Memory, Health and Aging (Cache County Study), and the subjects of European descent used in the Human Genome Project, the Centre d'Etude du Polymorphisme Humain (CEPH) subjects.

1. The Cache County Study represents one of the foremost databases in the world for the study of normative aging and dementias, and was established in 1994 by **Utah State University** researchers to provide population-based incident cohorts of dementia for study. The Cache County Study is a population-based longitudinal investigation of the risk factors for dementia. The entire cohort has been followed since establishment, with careful identification of prevalent and incident cases of dementia, and characterization of genetic and environmental risk factors for each individual. Working with Dr. Ron Munger and colleagues, we added information on more than 5000 Cache County senior residents to UPDB with 99.6% linking to existing UPDB records; of those, 76% have multi-generational families.

2. Although it is not well known, 47 of the 60 large, multi-generational families who donated their DNA to CEPH, and used by the Human Genome Project, were recruited by University of Utah researchers. The DNA from these people has been a critical resource in mapping studies that identified predisposing genes for many disorders over the past two decades. Of the original CEPH families, 41 continue to participate in the **Utah Genetic Reference Project**, run by Dr. Mark Leppert. We have linked 94% of these 577 family members to the UPDB, and their larger pedigrees are available for study.

An improved web page for UPDB was developed with the assistance of the Office of Communications and Public Affairs at Huntsman Cancer Institute. It includes new features and can be viewed at <http://www.hci.utah.edu/groups/ppr/>

RESEARCH USING UPDB

On-going

1. A Study of Cancer Rates and TCE Ground Water Contamination

Principal Investigator: Wayne Ball
Department: Department of Health
Data used: genealogy, cancer registry, driver license

2. The Intermountain States Registry of Childhood Rheumatic Disease

Principal Investigator: John Bohnsack
Department: Pediatrics
Data used: genealogy, birth certificates

3. High Risk Familial Colon Cancer: Genetics & Phenotype

Principal Investigator: Randall Burt
Department: Internal Medicine, Division of Gastroenterology
Data used: genealogy, death certificates, cancer registries, driver licenses, DRC

4. High Risk Breast Cancer Clinic

Principal Investigator: Sandra Buys
Department: Internal Medicine, Division of Oncology
Data used: genealogy, cancer registries, death certificates, birth certificates, driver licenses

5. A Genealogical Analysis of Longevity

Principal Investigator: Nicola Camp
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificate, cancer registry, driver licences

6. Genetic Analysis Techniques for Common Cancers

Principal Investigator: Nicola Camp
Department: Genetic Epidemiology
Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

7. Familiality Investigation of Clinical Characteristics of Prostate Cancer

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy

8. Familiality Investigation of Chronic Pain and Treatment Responses

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, DRC, driver licenses

9. Genetic Epidemiology of Prostate Cancer

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

10. Analysis of Familiality by Phenotype

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, cancer registries, birth certificates, DRC

11. Genetics of Familial Aneurysms

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, DRC, driver licenses

12. Genetic Analysis of Colorectal Cancer

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

13. Identification of Chronic Lymphocytic Leukemia (CLL) Predisposition Loci

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology

Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

14. Identification of Melanoma Predisposition Loci

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

15. Genetics of Breast Cancer

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

16. Fine Mapping and Isolation of the Familial Wilm's Tumor Gene FWT1

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

17. Familiality Student Activities

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: all

18. Inherited Predisposition to Type II Diabetes

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, driver licenses

19. Development of a Registry for Familial Pancreatic Cancer

Principal Investigator: James DiSario
Department: Huntsman Cancer Institute
Data used: genealogy, death certificates, cancer registries, driver licenses

20. Co-Ancestry in Primary Pulmonary Hypertension
- Principal Investigator: Gregory Elliott
Department: Internal Medicine, Division of Pulmonary Medicine
Data used: genealogy, death certificates
21. Role of Clonal Lymphocytosis of Unknown Significance (CLUS) in the Multi-Step Pathogenesis of Familial Chronic Lymphocytic Leukemia (CLL)
- Principal Investigator: Martha Glenn
Department: Internal Medicine
Data used: genealogy, cancer registries,
22. Role of Family History in Cardiovascular Mortality of Hemodialysis Patients
- Principal Investigator: Alexander Goldfarb
Department: Internal Medicine, Division of Nephrology
Data used: genealogy, death certificates, driver licenses
23. The Familial Component of Transplant Outcome
- Principal Investigator: Alexander Goldfarb
Department: Internal Medicine, Division of Nephrology
Data used: genealogy, death certificates, DRC, driver licenses
24. Chronic Respiratory Failure in Children
- Principal Investigator: Melissa Gowans
Department: Pediatrics
Data used: death certificates
25. An influence diagram for the management of community-acquired pneumonia
- Principal Investigator: Peter Haug/Daniel Aronsky
Department: Medical Informatics
Data used: death certificates
26. Origins of Higher Order Multiple Pregnancies
- Principal Investigator: Ivan Huang
Department: Obstetrics & Gynecology
Data used: birth certificates

27. Effectiveness of Utah's Shaken Baby Prevention Program

Principal Investigator: Heather Keenan
Department: Pediatrics
Data used: birth certificates

28. Familial Aggregation and Coaggregation of Cancer

Principal Investigator: Richard Kerber
Department: Oncological Sciences, Division of Public Health Sciences
Data used: genealogy, birth and death certificates, Utah Cancer Registry, driver licenses

29. The Cache County Family-Based Cohort Study on Aging

Principal Investigator: Richard Kerber
Department: Huntsman Cancer Institute
Data used: genealogy, birth and death certificates, driver licenses

30. Genetic Characterization of Cancer Risk in Families

Principal Investigator: Richard Kerber
Department: Huntsman Cancer Institute
Data used: genealogy, birth and death certificates, Utah Cancer Registry, driver licenses

31. Familiality of Psoriasis in Utah

Principal Investigator: Gerald Krueger
Department: Dermatology
Data used: genealogy

32. Genetic Characterization of Novel Subtypes of Inherited Neuropathies

Principal Investigator: Victoria Lawson
Department: Neurology
Data used: genealogy, DRC

33. The Tom C. Mathews Familial Melanoma Research Clinic

Principal Investigator: Sancy Leachman
Department: Dermatology
Data used: genealogy, death certificates, cancer registries, driver licenses

34. Familiality of Diabetes and Diabetic Complications in Utah
- Principal Investigator: Donald McClain
Department: Division of Endocrinology
Data used: genealogy
35. Genetic Study of Extended Pedigrees with Autism
- Principal Investigator: William McMahon
Department: Psychiatry
Data used: genealogy, birth and death certificates, driver licenses
36. Rocky Mountain Cancer Genetics Coalition
- Principal Investigator: Geri Mineau
Department: Huntsman Cancer Institute
Data used: genealogy, death certificates, cancer registries, driver licenses
37. Pregnancy Outcomes in Childhood Cancer Survivors
- Principal Investigator: Geri Mineau
Department: Huntsman Cancer Institute
Data used: genealogy, birth and death certificates, fetal death certificates, Utah Cancer Registry, driver licenses
38. Genetic Epidemiology of Breast Cancer
- Principal Investigator: Susan Neuhausen
Department: University of California, Irvine
Data used: genealogy, death certificates, cancer registries
39. W. M. Keck Foundation, University of Utah Genetic Reference Project
- Principal Investigator: Andy Peiffer
Department: Human Genetics
Data used: genealogy, birth and death certificates
40. Utah Infertility Registry-Polycystic Ovary Syndrome (UIR-PCOS)
- Principal Investigator: C. Matthew Peterson
Department: Obstetrics & Gynecology
Data used: genealogy, DRC

41. Intermountain Multiple Sclerosis Project
- Principal Investigator: John Rose
 Department: Neurology
 Data used: genealogy, DRC
42. Utah Rheumatoid Arthritis Project
- Principal Investigator: Allen Sawitzke
 Department: Internal Medicine, Division of Rheumatology
 Data used: genealogy, DRC, driver licenses
43. Genetic and Molecular Characterization of Interstitial Lung Disease
- Principal Investigator: Mary Beth Scholand
 Department: Internal Medicine, Pulmonary Division
 Data used: genealogy, death certificates
44. Genetic Influences in Autism in Tuberous Sclerosis
- Principal Investigator: Susan L. Smalley
 Department: Psychiatry, UCLA
 Data used: genealogy
45. Kinship and Socio-Demographic Determinants of Mortality
- Principal Investigator: Ken Smith
 Department: Family & Consumer Studies
 Data used: genealogy, death certificates
46. Effects of Cancer Risk on Fertility in a Large Kindred with Hereditary Breast and Ovarian Cancer
- Principal Investigator: Ken Smith
 Department: Family and Consumer Studies
 Data used: birth certificates
47. The Utah Study of Fertility, Longevity and Aging
- Principal Investigator: Ken Smith
 Department: Family & Consumer Studies
 Data used: genealogy, birth and death certificates, cancer registries, driver licenses

48. Study of Time to Pregnancy in Normal Fertility

Principal Investigator: Joseph Stanford
Department: Family & Preventive Medicine
Data used: birth certificates

49. Intergenerational Paternal Predisposition to Obstetric Complications

Principal Investigator: Michael Varner
Department: Obstetrics/Gynecology
Data used: genealogy, birth and death certificates, Utah Cancer Registry, fetal death data, driver licenses

50. Thyroid Disease in Persons Exposed to Radioactive Fallout from Atomic Weapons Testing at the Nevada Test Site: Phase III MORTALITY STUDY COMPONENT

Principal Investigator: George White
Department: Family and Preventive Medicines
Data used: birth and death certificates

51. Cancer risks in mothers of twins and their offspring

Principal Investigator: David Whiteman
Department: Epidemiology, Queensland Institute of Medical Research, Australia
Data used (under a CDITA): genealogy, birth and death certificates, Utah Cancer Registry

52. Genetics and Molecular Studies of Eye Disease

Principal Investigator: Kang Zhang
Department: Ophthalmology
Data used: genealogy, DRC, driver licenses

New Projects

1. Molecular Analysis of FFPE Cancer Tissue

Principal Investigator: Philip Bernard
Department: Pathology
Data used: genealogy, death certificates, DRC

2. Inflammatory bowel disease in Utah: Using the Utah Population Database to assess familial risk

Principal Investigator: Stephen Guthery
Department: Pediatrics
Data used: genealogy, birth and death certificates, DRC

3. Spatial Variation in Body Mass Index

Principal Investigator: Jessie Fan
Department: Family & Consumer Studies
Data used: genealogy, birth certificates, DLD

4. Retrospective Chart Review for Veteran Suicide Identification

Principal Investigator: Michelle Moskos
Department: Pediatrics
Data used: death certificates

5. Randomized, Double Blind, Placebo-Controlled, Multicenter Study of a Subcutaneous Formulation of Icatibant for the Treatment of Hereditary Angioedema

Principal Investigator: Gerald Gleich
Department: Dermatology
Data used: genealogy, DRC

6. Intermountain Heart Collaborative Study

Principal Investigator: J. Brent Muhlestein
Department: LDS Hospital
Data used: DLD

7. Validating prediction models of kidney transplant outcome using local data

Principal Investigator: Hongying Tang
Department: Medical Informatics
Data used: DRC, death dates

8. Using Record Matching Techniques to Identify Duplicate Person Records

Principal Investigator: Scott DuVall
Department: Medical Informatics
Data used: all

9. Linkage of Utah Birth Defects Network surveillance data with UPDB
Principal Investigator: Marcia Feldkamp
Department: Utah Department of Health
Data used: genealogy, birth certificates, death certificates, UCR, DRC

10. Familial kinship analysis in patients with Mullerian anomalies
Principal Investigator: Ahmad Hammoud
Department: Obstetrics & Gynecology
Data used: genealogy, birth certificates

11. Familial Analysis of Pelvic Organ Prolapse (POP) and Urinary Incontinence
Principal Investigator: Lisa Cannon-Albright
Department: Biomedical Informatics
Data used: genealogy, birth certificates, death certificates, UCR, DRC, DLD

12. Promoting Colonoscopy in Rural High-Risk Families via Telegenetics
Principal Investigator: Anita Kinney
Department: Huntsman Cancer Institute
Data used: genealogy, UCR

Single search or pilot projects

1. Robert Glasgow, Department of Surgery, requested information on the number of individuals in the GenMed file with gallstone disease. (4/06)
2. Lisa Cannon-Albright, Division of Genetic Epidemiology, Department of Medical Informatics, requested information on the number of records of individuals with auditory processing disorders identifiable through the GenMed file. (5/06)

Inactive projects

1. Consanguinity and prereproductive mortality
Principal Investigator: Lynn Jorde
Department: Human Genetics
Datasets used: genealogy, birth and death certificates

2. Colon Cancer in Reference Linkage Families

Principal Investigator: Mark Leppert
Department: Human Genetics
Datasets used: research data of Dr. Eldon Gardner; genealogy, cancer registries

3. Heredity and Environmental Factors Affecting BPH

Principal Investigator: A. Wayne Meikle
Department: Internal Medicine, Division of Endocrinology
Datasets used: genealogy, death certificates, birth certificates

Projects completed or access to UPDB no longer necessary

1. Analysis of High Risk Cancer Pedigrees

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, Utah Cancer Registry, driver licenses

2. Genetics of Idiopathic Dilated Cardiomyopathy

Principal Investigator: Lisa Cannon-Albright
Department: Division of Genetic Epidemiology
Data used: genealogy, death certificates, driver licenses

3. Role of Family History in Cardiovascular Mortality of Renal Transplant Patients

Principal Investigator: Arsalan Habib
Department: Internal Medicine, Division of Nephrology
Data used: genealogies, death certificates, DRC, driver license

4. Hyperparathyroidism-Jaw Tumor

Principal Investigator: Maurine Hobbs
Department: Internal Medicine, Division of Endocrinology
Data used: genealogy, Utah Cancer Registry, death certificates

5. Optimal Strategies of Breast Cancer Surveillance

Principal Investigator: Andrei Y. Yakovlev

Department:

University of Rochester

Data used:

genealogy, birth and death certificates, Utah Cancer Registry

RESEARCH USING HCI RESOURCES

High Risk Breast Cancer Clinic (HRBCC) and Registry resources: On-going projects

1. Genetic and Environmental Modifiers of Penetrance in BRCA1 and BRCA2 Mutation Carriers

Principal Investigator: Saundra Buys¹
Department: Internal Medicine, Division of Hematology/Oncology

2. Ovarian Cancer Screening Study

Principal Investigator: Saundra Buys
Department: Internal Medicine, Division of Hematology/Oncology

3. Psychological Assessment of HRCC Breast Cancer Participants Following Genetic Testing

Principal Investigator: Anita Kinney
Department: Nursing

4. Genetic Epidemiology of Breast Cancer: BRCA1 and BRCA2

Principal Investigator: Susan Neuhausen
Department: University of California, Irvine

5. Cancer Susceptibility Genetic Testing and Adult Sibling Relationships

Principal Investigators: Ken Smith/Heidi Hamann
Departments: Family and Consumer Studies/Psychology

Projects completed or access to HRBCC resources no longer necessary:

1. Effect of Radiotherapy After Breast-conserving Treatment in Women with Breast Cancer and Germline BRCA1/2 Mutations

Principal Investigator: David Gaffney
Department: Radiation Oncology

1 Dr. Buys is the Rocky Mountain Cancer Genetics Coalition Co-Principal Investigator for this multi-site project accessing Registry information through the Cancer Genetics Network

2. Validation of BRCA1 & BRCA2 Carrier Probability Models

Principal Investigators: Richard Kerber
Department: Oncological Sciences

**Familial Colon Cancer Clinic (FCCC) and Registry resources:
On-going projects**

1. Chemoprevention of Duodenal Polyps in FAP

Principal Investigator: James DiSario
Department: Internal Medicine, Division of Gastroenterology

2. Behavioral and Psychosocial Issues Related to Screening and Genetic Testing for Familial Adenomatous Polyposis

Principal Investigator: Anita Kinney
Department: Nursing

PUBLICATION REVIEWS - UPDB

PAPERS

1. Larson, A, Leachman, S, Eliason, M and Cannon-Albright, L. Population-based assessment of non-melanoma cancer risk in relatives of cutaneous melanoma probands. Approved August 12, 2005.
2. Aagard, K, Holmgren, C, Lacoursiere, Y, Fraser, A, Mineau, G and Varner, M. Preeclampsia and subsequent risk of cancer. Approved August 12, 2005.
3. Naiman, N, Goldfarb-Rumyantzev, A, Habib, A, Lin, S-j, Wang, B-j, Cheung, A and Cannon-Albright, L. Is Family History of ESRD Another Risk Factor for Cardiovascular Disease? Approved October 24, 2005.
4. Goldfarb-Rumyantzev, A, Cheung, A, Wang, B-j, Lin, S-j, Baird, B, Naiman, N, and Cannon-Albright, L. A Population-Based Assessment of the Familial Component of Chronic Kidney Disease Mortality. Approved October 24, 2005.
5. Eliason, M, Larson, A, Florell, S, Zone, J, Cannon-Albright, L, Samlowski, W and Leachman, S. Population-based prevalence of *CDKN2A* mutations in Utah melanoma families. Approved October 24, 2005.
6. Allen-Brady, K, Cannon-Albright, L, Neuhausen, S, Camp, N. A Role of *XRCC4* in Age at Diagnosis and Breast Cancer Risk. Approved January 23, 2006.
7. Albright, F.S., Orlando, P, Pavia, A and Cannon-Albright, L. Evidence for a Heritable Predisposition to Death from Influenza using genealogical data linked to 100 years of Utah death certificate data. Approved April 21, 2006.
8. Gowans, M, Keenan, H and Bratton, S. The Population Prevalence of Children Receiving Home Ventilation in Utah. Approved June 1, 2006.
9. Vogl, F, Badzioch, M, Steele, L, Cannon-Albright, L, Neuhausen, S and Goldgar, D. Risks of cancer due to a single *BRCA1* mutation in an extended Utah kindred. Approved June 1, 2006.
10. Smith, K, Mineau, G, Garibotti, G and Kerber, R. Effects of Childhood and Middle-Adulthood Family Conditions on Later-Life Mortality: Evidence from the Utah Population Database, 1850-2002. Approved June 14, 2006.

ABSTRACTS

1. Baird, J, Zabriskie, N, Bernstein, P, Gomez, R, MacArthurs, R, Yang, Z, Pearson, E and Zhang, K. Genetic Epidemiology of Age-Related Macular Degeneration Using the Utah Population Database. Approved December 1, 2005.

2. Guthery, S. Analysis of the Utah Population Database demonstrates elevated risk of IBD among family members of IBD-affected individuals, and is a source for large pedigrees in which IBD is aggregating. Approved December 6, 2005.
3. Smith, S. Using the UPDB to Assess Familial Risk of Primary Open Angle Glaucoma. Approved December 6, 2005.
4. Cannon-Albright, L, and Albright, F. Suggestive Evidence for a Genetic Component for Predisposition to Death from Influenza from a Genealogy linked to 100 years of death certificate data for Utah. Approved February 13, 2006.
5. Cannon-Albright, L and Albright, F. Evidence for a heritable component to Chronic Fatigue Syndrome. Approved March 22, 2006.
6. DuVall, S, Conrads, J, Fraser, A and Mineau, G. A profile of the duplicate records in the University of Utah Health Science Center Enterprise Data Warehouse. Approved April 28, 2006.
7. Hammoud, A. Familial kinship analysis in patients with Mullerian anomalies. Approved June 30, 2006.

APPENDIX A

RGE Review Committee

July 1, 2006

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