Utah Population Database

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05/25/22
Center on Aging Annual Retreat
1966, Utah Cancer Registry
- Founded by Charles Smart, MD

1974-1978
- 1974, computerized genealogy initiated (Mark Skolnick, PhD)
- 1975, linked to UCR for cancer genetics (Mark Skolnick, PhD)
- 1977, cardiovascular research (Roger Williams, MD)
- 1978, population studies (Lee Bean, PhD)

1982, creation of the RGE
- Executive Order of the Governor of Utah
- Data governance
- Biomedical and health-related research
Recent History

1990s – now
Institutionalization
Development and Growth

Geri Mineau, PhD
Ken Smith, PhD
Karen Curtin, PhD
Nicola Camp, PhD
Major Data Contributors
Data Availability
Utah Population Database

Source Records
- Original Family History Records
- Vital Records
- Medical Records
- Additional Records
- Externally Linked Records

Other Notations
- Current
- Snapshot

Data sources may not be complete or fully accurate.
Person-oriented records

• 11 million unique individuals

• Multiple records for an individual are carefully matched

• Additional dimensions
  • Geographic mapping, environmental exposures, SDOH
  • Longitudinal – many events over an individual’s life
  • Investigator data
UDPB Privacy and Confidentiality

- Data agreements
- Utah Health Data Committee review
- RGE review
- Secure storage locations
Utah Population Database

rare
valuable
UPDB study portfolio

- Cancer: 45%
- OB/child: 25%
- Chronic: 25%
- Aging: 5%
Genetic/Familial Risk

- Understand familial clustering
- Identify high-risk families
Cancer
Heart and lung disease
Immune diseases
Metabolic diseases
Neurological disorders
Reproductive phenotypes

Utah Genome Project
https://uofuhealth.utah.edu/center-genomic-medicine/research/utah-genome-project.php
Shared genomic segment analysis in a large high-risk chronic lymphocytic leukemia pedigree implicates CXCR4 in inherited risk

Julie E. Feusier, Michael J. Madsen, Brian J. Av Hu, Afaf E. G. Osman, Martha J. Glenn, Nicola

A

SGS
Ind1
Ind2
Ind4
Ind5
Ind6
Ind7
Ind8

Genet
MAP3K1
BAX
APC1
NTRK1
CIR

B

CXCR4

0
100
200
300
400
500
600
700
800
900
1000
tissue / cell line / blood cell type

Th5 D7B

Journal of Translational Genetics and Genomics

Pedigree symbols:
- CLL/SLL
- MBL
- Other hematologic malignancy
- Solid cancer
- Other hematologic malignancy and solid cancer
Hypertensive Disorders of Pregnancy Increases Risk of Developing Neovascular Age-related Macular Degeneration in Later Life

Karen Curtin, PhD,1,2,5 Lauren H. Theilen, MD,3 Alison Fraser, MSPH,2 Ken R. Smith, PhD,2,4 Michael W. Varner, MD,3 and Gregory S. Hageman, PhD5
Hypertensive disorders during pregnancy & risk choroidal neovascular AMD

Implications: earlier screening detection of choroidal neovascularization
Acute effects of air pollutants on spontaneous pregnancy loss: a case-crossover study

Claire L. Leiser M.S.P.H. a, b, c, Heidi A. Hanson Ph.D., M.S. a, b, c, Kara Sawyer M.D. a, Jacob Steenblik M.P.H., M.H.A. a, Ragheed Al-Dulaifaini M.D., M.P.H., M.Sc. a, d, e, Troy Madsen M.D. a, Karen Gibbins M.D. a, James M. Hotaling M.D. a, Yetunde Oluseye Ibrahim M.D. a, James A. VanDerslice Ph.D. a, Matthew Fuller M.D. a

Air pollution 'as bad as smoking in increasing risk of miscarriage'
Air Quality System (AQS)

AQS User Support is provided through your Regional EPA representative.

If 7-day average of NO₂ raises from 25th to 75th %ile, risk pregnancy loss increase 11%
Disparities in Cardiovascular Disease Risk Among Hispanic Breast Cancer Survivors in a Population-Based Cohort

Qingqing Hu, PhD, Chun-Pin Chang, PhD, Kerry Rowe, PhD, John Snyder, PhD, Vikrant Deshmukh, PhD, Michael Newman, MS, Allison Fraser, MS, Ken Smith, PhD, Lisa H. Gren, PhD, Christina Porucznik, PhD, Joseph B. Stanford, MD, MSPH, David Gaffney, MD, N. Lynn Henry, MD, PhD, Ivette Lopez, PhD, Mia Hashibe, PhD

The risks of cardiovascular disease at 1-5 years follow-up among Hispanic and non-Hispanic White breast cancer survivors in comparison with general population cohorts of women

<table>
<thead>
<tr>
<th>Clinical Classification</th>
<th>Hispanic Breast cancer survivors N (%)</th>
<th>General population N (%)</th>
<th>HR (99% CI)</th>
<th>Hispanic Breast cancer survivors N (%)</th>
<th>General population N (%)</th>
<th>HR (99% CI)</th>
<th>P</th>
<th>heterogeneity</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 Diseases of the circulatory system</td>
<td>1079 (60.8)</td>
<td>2793 (47.9)</td>
<td>1.94 (1.49 to 2.53)</td>
<td>10403 (66.3)</td>
<td>31782 (53.3)</td>
<td>1.38 (1.33 to 1.43)</td>
<td>.01</td>
<td></td>
</tr>
</tbody>
</table>
data science
Familial Multi-Phenotype Configurations (FMC)

5,045
Overall

Family Study Designs Informed by Tumor Heterogeneity and Multi-Cancer Pleiotropies: The Power of the Utah Population Database

Heidi A. Hanson ☐; Claire L. Leiser; Michael J. Madsen; John Gardner; Stacey Knight ☐; Melissa Cessna; Carol Sweeney;
Jennifer A. Doherty; Ken R. Smith; Philip S. Bernard; Nicola J. Camp ☐
looking to the future
Utah Population Database

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Andrew Post, MD, PhD
Katharine Ullman, PhD
Michael Varner, MD

https://uofuhealth.utah.edu/huntsman/utah-population-database/