# Resources for Type 1 Diabetes Investigators

The Genetics of Kidneys in Diabetes (GoKinD) collection has nearly 10,000 DNA, serum, plasma and urine samples, plus genetic and clinical data, from more than 1,700 adults with type 1 diabetes in the United States and Canada. Of those, 818 have had diabetes at least 10 years and have developed kidney disease, a common complication of diabetes. The other 893 have had diabetes at least 15 years but do not have kidney disease. Also in the collection are data and samples from 1,096 parents (548 sets).

Researchers can apply for DNA, extensive clinical data and some genetic data from GoKinD at http://www.gokind.org/access; serum, plasma and urine samples will be made available later. Methods of treatment, insulin doses, complications, smoking history and other data have been documented for all GoKinD participants. Also, DNA has been genotyped for genes well-known to predispose to type 1 diabetes. To protect the privacy of patients and families, researchers do not have access to names and other identifying information.

Both NIH and JDRF will separately consider requests to fund research on GoKinD data and samples. NIH grant applications are at http://grants.nih.gov, and resources for type 1 diabetes research are listed at www.niddk.nih.gov/fund/diabetesspecialfunds/funding.htm. JDRF grant applications are under the research tab at www.jdrf.org.

NIH, JDRF and CDC collaborated on GoKinD. NIH supported the study through a special fund for type 1 diabetes research established by Congress in 1997 and coordinated by

Genetics of Kidneys in Diabetes (GoKinD) Study - Microsoft Internet Explorer

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Address http://www.gokind.org/access/about.cgi

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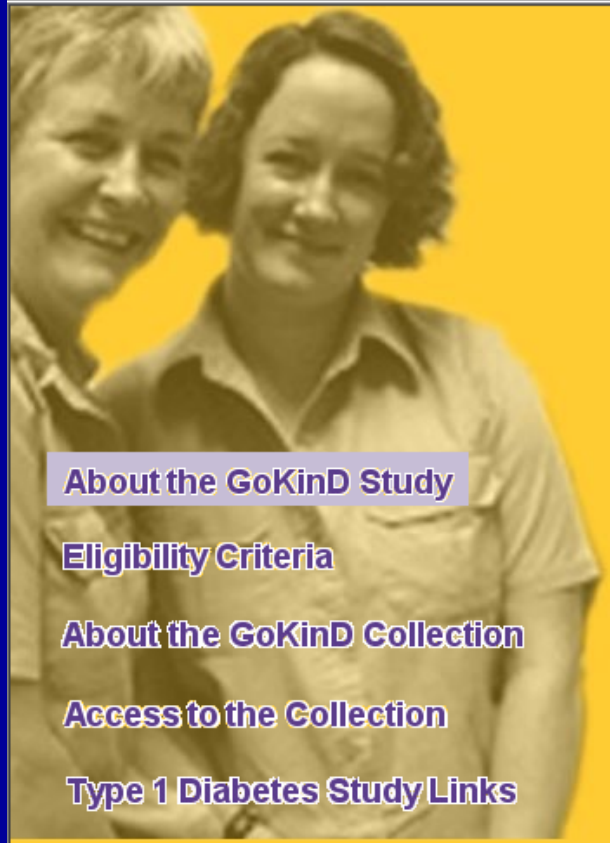

About the GoKinD Study

Eligibility Criteria

About the GoKinD Collection

Access to the Collection

Type 1 Diabetes Study Links

GoKinD

*Genetics of Kidneys in Diabetes Study*

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## About the GoKinD Study

The purpose of the Genetics of Kidneys in Diabetes (GoKinD) Study is to establish a repository of DNA and clinical information from adults with long-term Type 1 diabetes, with or without kidney disease, along with their parents. The fundamental aim of GoKinD is to facilitate investigator-driven research into the genetic basis of diabetic kidney disease as well as other issues concerning Type 1 diabetes. This clinically well-characterized population provides a scientific resource maintained under the joint stewardship of JDRF, the Joslin Diabetes Center, GWU and CDC. All collaborating organizations are committed to establishing and maintaining access to the data set as much as is feasible.

Recruitment of new families for the study is closed as of November 2004. In the three and a half years of the recruitment phase the GoKinD study has screened more than 5500 participants by phone and in person.
CLICK HERE for more information about recruitment.
CLICK HERE for a list of GoKinD principal investigators.

# GoKinD Participants

- Cases:

  Adult, 18-54, living in US or Canada

  Type 1 diabetes at least 10 years, with kidney disease

  Persistent proteinuria (2/3 ACRs >300 ugm/mg) or ESRD

- Controls:

  Adult, 18-59, living in US or Canada

  Type 1 diabetes at least 15 years, without kidney disease

  Has never been treated with ACE inhibitors, no current anti-hypertensive medication

  Normoalbuminuria (2/3 ACR < 20 ugm/mg)

- All trios are complete – 2 living parents.

- Last study IDs issued Oct. 31, 2004

# GoKinD Characteristics Tables as of 7 March 2005

Case trios = 267; Case singletons = 627  Total cases = 894

Control trios = 317; Controls = 618  Total controls = 935

Final eligibility calls will be made March 31, 2005.

# GoKinD Participant Samples

- Clinical Data
- Genetic data limited to: HLA (DRB1, DQA1, DQB1), INS
- DNA
- Cryopreserved lymphocytes
- Serum
- Plasma
- Urine
- Immortalized cell line (EBV-transformed)

- DNA samples will be distributed in August 2005

# GoKinD Clinical Data

Race

Gender

Age at Entry

BMI

Waist Circumference

Smoking (Ever/current)

Serum Total Cholesterol

HDL-cholesterol

Serum creatinine

Serum cystatin C

Urine albumin

Urine creatinine

ESRD

Non-ESRD:

- ACR
- GFR (MDRD, C-G)
- 100/creatinine
- 100/cystatin C

Hypertension

Antihypertensive Treat.

Blood Pressure

Living Parents

Retinopathy

Cardiovascular Disease

Neuropathy

Age at diabetes

Diabetes duration

Pancreas transplant?

Insulin regimen

HbA1c (%)

Other autoimmune disease

# GoKinD Clinical QC Data (11/8/2004 data)

| Test | n | Coefficient of Reliability (95% Confidence Interval) |
|---|---|---|
| Blood Hemoglobin $A_{1c}$ | 128 | 0.9891 (0.9846 - 0.9923 ) |
| Serum Total Cholesterol | 111 | 0.9613 (0.9442 - 0.9732) |
| Serum HDL-cholesterol | 103 | 0.9667 (0.9512 - 0.9773) |
| Serum Creatinine | 108 | 0.9926 (0.9892 - 0.9949) |
| Serum Cystatin C | 74 | 0.9731 (0.9576 -0.9829) |
| Urine Albumin | 111 | 0.934 (0.9055 - 0.9542) |
| Urine Creatinine | 111 | 0.9467 (0.9234 - 0.963) |
| Albumin/Creatinine Ratio | 111 | 0.9126 (0.8753 - 0.9391) |

Replicate samples from 10% of participants were used as QC. CBL processed blind duplicate samples. All aspects of process were QC'ed.

# GoKinD Informed Consent

- Samples may be used for the study of the genetic risk factors for Type 1 diabetes and its complications
- Samples and information will be shared: “we will give your DNA or other cell parts to researchers”
- No cell lines will be distributed.
- Results of standard medical tests returned to the patient, but no information from DNA or cells
- No identifying information will be released.
- No guarantee of personal benefit and no expectation of personal profit
- Voluntary withdrawal at any time
- Consent for future contact (follow up)

# Requests for Access

- Requests will be considered by separate Access Committee
- Criteria for access:
  - Scientific rationale
  - Amount of DNA requested
  - Appropriate study design
  - QC plan adequate
  - Appropriate Use
  - Environment and facilities
  - Plan for handling data
  - IRB FWA number
- Review of requests for access of renewable material **will not** consider scientific merit.

# Requirements for Approved Investigators

- Agree to report all data generated using GoKinD samples back to GoKinD database (12 months)
- Agree to provide documentation of IRB approval
- Agree to comply with the provisions of informed consent
- Agree to conduct the research indicated in the approved request
- Agree not to identify or attempt to identify individual participants
- Agree not to distribute GoKinD materials to third parties
- Agree not to use GoKinD materials in human experimentation
- Agree to provide funders with copies of publications
- Agree to acknowledge GoKinD

# Other Populations

NIH-supported:

- EDIC
- FIND – T1 and T2

EU-supported:

- EUROGEDIC
- EURODIAB

Diabetes UK- and JDRF-supported:

- Warren III (GoKinD UK)

Wellcome Trust- and JDRF-supported:

- Nephropathy Family Study

# GoKinD Organization

Executive Committee:

Joslin Diabetes Center (Warram, Rogus, Krolewski)

George Washington University Bioinformatics Center (Cleary)

Centers for Disease Control (Cordovado, Mueller)

University of Minnesota (Steffes, Bucksa)

Matthews Media Group

JDRF

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