

REC'D AUG 23 2011

DIABETES REGISTRY
CONSENT TO PARTICIPATE IN A DIABETES REGISTRY

IR Number: 5871

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WHY IS THIS DIABETES REGISTRY BEING DONE?

We are inviting you to participate in this registry because you have diabetes or have a family member with diabetes. The purpose of this registry is to have a list of people who might be willing to participate in future research studies. Information from this registry will be used to contact possible participants.

WHAT IS INVOLVED IN THE DIABETES REGISTRY?

This diabetes registry is a database of people with diabetes and people who have a relative with diabetes. With your permission, the database will contain the personal information you give us from the attached form, or data from other diabetes research studies that you have participated in may be included. This registry will be used to contact and inform you about diabetes studies that you may be eligible for in the future. If you are contacted about participation in a future study, all the information concerning that study will be explained to you at that time. You are under no obligation to participate in any study you are contacted about.

WHAT ARE THE RISKS OF BEING IN THE DIABETES REGISTRY?

There are no health risks in this diabetes registry. The only potential risk to you would be possible lack of confidentiality.

ARE THERE BENEFITS TO TAKING PART IN THE DIABETES REGISTRY?

There are no direct benefits in participating in this registry. However, you will receive periodic newsletters providing information about diabetes research, and you may be contacted about future diabetes research as a result of your participation in this registry.

WHAT ABOUT CONFIDENTIALITY?

All efforts will be made to keep your personal information confidential, however, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Benaroya Research Institute at Virginia Mason staff, and the Institutional Review Board will have access to your information. Your research records will be kept indefinitely unless otherwise indicated. Your personal identity will not be revealed in any publication of study results.

WHAT ARE THE COSTS?

There is no cost to you to participate in this registry, and no costs should be incurred as a result. You will receive no payment or any type of compensation for participating.





DIABETES REGISTRY CONSENT TO PARTICIPATE IN A DIABETES REGISTRY

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Taking part in this registry is voluntary. At any time you may choose not to take part or may ask that your name be removed from the registry by asking one of the investigators on this form. Choosing not to take part or removing your name from the registry will not result in any penalty or loss of benefits to which you are entitled, and will in no way jeopardize your future medical or research care.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

For questions about your rights as a research participant, contact the BRI Institutional Review Board (IRB) Administrator at (206) 341-0787. The IRB Administrator manages the IRB, which is a group of people who review this research to protect your rights and welfare.

PARTICIPANT'S AUTHORIZATION

I agree to allow information about me as described above to be included in this registry, and would be willing to be contacted regarding possible participation as a research volunteer in diabetes research studies, but I am free to refuse to participate in any study if contacted.

I have read and understand this consent form and agree to take part in this registry. By signing this form I do not give up my rights, if any, which may be available to me by law. My signature also indicates that I have been given a copy of this consent form.

PARTICIPANT'S SIGNATURE
(or legally authorized representative)

PARTICIPANT'S NAME (print)

DATE

PARENT/LEGAL GUARDIAN'S SIGNATURE
(for participants less than 18 years old)

PARENT/LEGAL GUARDIAN'S
NAME (print)

DATE

Research staff only

 Event/Other**DIABETES PATIENT and FAMILY MEMBER REGISTRY**

Today's date ___/___/___

Birth date ___/___/___

Sex (M or F)

Name: _____

Address: _____

City, State, Zip _____

Phone: Home (_____) _____ Work (_____) _____

E-mail address _____

Physician's name: _____ Phone (_____) _____

Address: _____

City, State, Zip _____

• **Do you have diabetes? (check one)** **Yes, I have diabetes**

Do you know the type of diabetes you have? (check one)

 Type-1 (formerly called Juvenile onset diabetes) Type-2 (formerly called Adult onset diabetes) Other type of diabetes (specify) i.e. diabetes during pregnancy _____ Don't know

Do you have a relative(s) with diabetes?

 Yes, Do they have Type-1 or Type-2 diabetes or Other/Don't know No **No, I do not have diabetes, but I have a relative(s) with diabetes**

Do you know the type of diabetes they have? (check all that apply)

 Type-1 (formerly called Juvenile onset diabetes) Type-2 (formerly called Adult onset diabetes) Other type of diabetes (specify) i.e. diabetes during pregnancy _____ Don't know

Please complete the following information, to your best knowledge, as it relates to you if you have diabetes or to your relative who has diabetes:

• **Age at diagnosis of diabetes:** _____ **Date of diagnosis:** _____

- **Medications taken when first diagnosed with diabetes:**
 Insulin Oral medications No medication Unknown
- **Medications currently taken for diabetes (check all that apply)**
 Insulin Oral medications No medication Unknown
- **Ethnic Background:** Caucasian African American Hispanic Other
 Asian American Native American Decline to state

**BENAROYA RESEARCH INSTITUTE AT VIRGINIA MASON (BRI)
 INVESTIGATIONAL STUDY PARTICIPANTS
 BILL OF RIGHTS**

The rights below are the rights of every person who is asked to be in a research study. As an investigational study participant, you have the following rights:

- 1) To be told what the study (research) is trying to find out.
- 2) To be told what will happen to you and whether any of the procedures, drugs, or devices is different from what would be in standard practice.
- 3) To be told about the frequency and/or important risks, side effects or discomforts of the things that will happen to you for research purposes.
- 4) To be told if you can expect any benefit from participating and, if so, what the benefit might be.
- 5) To be told the other choices you have and how they may be better or worse than being in the study.
- 6) To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study.
- 7) To be told what sort of medical treatment is available if any complications arise.
- 8) To refuse to participate at all, or to change your mind about participation after the study has started. This decision will not affect your right to receive the care you would receive if you were not in the study.
- 9) To receive a copy of the signed and dated consent form.
- 10) To be free of pressure when considering whether you wish to agree to participate in the study.
- 11) To be informed of any researcher's financial interest in the study.

If you have other questions, you should ask the researcher (doctor). In addition, you may contact the Institutional Review Board which is concerned with protection of volunteers in research projects. You may reach the committee office by calling (206)342-6916 Monday through Friday, or by writing the Institutional Review Board, Benaroya Research Institute, 1201 Ninth Avenue, Seattle, Washington 98101-2795.