

Please provide the following information for
our Pediatric Endocrine and Diabetes Database:
(Parent's complete this form for your diabetic child)

Name: _____

Parent's Name (if under 18 years of age): _____

Address (include city, state and zip):

Daytime phone: _____

Evening phone: _____

email address: _____

Date of birth: _____

Gender: _____ Male, _____ Female

If you have Diabetes
Please complete the following queries:

Have ____ Type 1 Diabetes, ____ Type 2 Diabetes

Date of diagnosis _____

Use Lantus? Yes/No

On an Insulin Pump? Yes/No

If use an insulin pump, what kind? _____

When did you start using a pump? _____

Please complete the attached Consent form and if between 7 and 18 years, the Assent form
and send both this completed questionnaire and the consent/assent form to:

Bonnie Baker
Stanford University Medical Center
300 Pasteur Dr., Room G 313
Stanford, CA 94305-5208
Fax: 650-725-8375

STANFORD UNIVERSITY - Research Consent Form



STUDY

Protocol Title: Pediatric Endocrine and Diabetes Patient Lists

Protocol Director: Darrell M. Wilson, MD Version D

IRB Approval Date: 4 August 2009; IRB Expiration Date: 3 August 2010

Imprint

Please check one of the following:

You are an adult subject in this study.

You are the parent or guardian granting consent for a minor in this study.

Print minor's name here: _____

The following information applies to the individual or to his/her minor child. If the subject is a minor, use of "you" refers to "your child".

FOR QUESTIONS ABOUT THE STUDY, CONTACT: Darrell Wilson, MD at G-313 Medical Center MC 5208, Stanford CA 94305, phone 650-723-5791.

DESCRIPTION: We are requesting your permission to include your information in a database so that we may contact you about future studies you might be interested in. If you agree, Dr. Wilson and his research study staff will include information such as your name, address, your gender, birthdate, when you were seen in clinic, and some information about why you are being seen in our clinics. We do NOT collect social security numbers. We may contact you about future studies that may be of interest to you. There are NO procedures, blood tests, X-rays or any alternation of your medical care by being in this database. We do NOT plan on sharing this database with anyone outside of the Division except as required by law.

RISKS AND BENEFITS: The only risk we are aware of is a very slight risk that information about you could get out. The benefits which may reasonably be expected to result from this study is to be aware of potential studies available at Stanford.

WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY.

Your decision whether or not to participate in this study will not affect your employment/medical care.

TIME INVOLVEMENT: Your participation in this experiment will take approximately a minute to review and sign this form.

ALTERNATIVES: The alternative is not to participate in this study.

COSTS: There is no cost to you for participating in this study

PAYMENTS: You will receive no payment for your participation.

Authorization To Use Your Health Information For Research Purposes

Because information about you and your health is personal and private, it generally cannot be used in this research study without your written authorization. If you sign this form, it will provide that authorization. The form is intended to inform you

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about how your health information will be used or disclosed in the study. Your information will only be used in accordance with this authorization form and the informed consent form and as required or allowed by law. Please read it carefully before signing it.

What is the purpose of this research study and how will my health information be utilized in the study?

We wish to keep a list of people who may be interested in future research studies so that we may contact them

Do I have to sign this authorization form?

You do not have to sign this authorization form. But if you do not, you will not be able to participate in this research study.

If I sign, can I revoke it or withdraw from the research later?

If you decide to participate, you are free to withdraw your authorization regarding the use and disclosure of your health information (and to discontinue any other participation in the study) at any time. After any revocation, your health information will no longer be used or disclosed in the study, except to the extent that the law allows us to continue using your information (e.g., necessary to maintain integrity of research). If you wish to revoke your authorization for the research use or disclosure of your health information in this study, you must write to: Dr Darrell Wilson, G313 Med Center, Stanford, CA 94305-5208.

What Personal Information Will Be Used or Disclosed?

Your health information related to this study, may be used or disclosed in connection with this research study, including, but not limited to your name, address, birthdate, gender, and when you were seen in clinic, and some information about why you are being seen in our clinics which could include information in your medical record concerning the condition we are see you for.

Who May Use or Disclose the Information?

The following parties are authorized to use and/or disclose your health information

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in connection with this research study:

- The Protocol Director Dr Wilson and his research team
- The Stanford University Administrative Panel on Human Subjects in Medical Research and any other unit of Stanford University as necessary
- Research Staff

Who May Receive or Use the Information?

The parties listed in the preceding paragraph may disclose your health information to the following persons and organizations for their use in connection with this research study:

The Office for Human Research Protections in the U.S. Department of Health and Human Services

Your information may be re-disclosed by the recipients described above, if they are not required by law to protect the privacy of the information.

When will my authorization expire?

Your authorization for the use and/or disclosure of your health information will expire 14 June 2051.

Signature of Participant

Date

Signature of Legally Authorized Representative

Date

Description of Representative's Authority to Act for Subject

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SUBJECT'S RIGHTS: If you have read this form and have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty. You have the right to refuse to answer particular questions.

CONFIDENTIALITY: Your individual privacy will be maintained in all published and written data resulting from the study. Subject information may be provided to federal and regulatory agencies as required.

Independent of the Research Team Contact: If you are not satisfied with the manner in which this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a research study subject, please contact the Stanford Institutional Review Board (IRB) to speak to an informed individual who is independent of the research team at (650)-723-5244 or toll free at 1-866-680-2906. Or write the Stanford IRB, Administrative Panels Office, Stanford University, Stanford, CA 94305-5401. In addition, please call the Stanford IRB at either (650)-723-5244 or toll free at 1-866-680-2906 if you wish to speak to someone other than the research team or if you cannot reach the research team.

The extra copy of this consent form is for you to keep.

SIGNATURE _____ **DATE** _____

The IRB determined that the permission of one parent is sufficient for research to be conducted under 45 CFR 46.404, in accordance with 45 CFR 46.408(b).

STANFORD UNIVERSITY - Research ASSENT Form



STUDY

Protocol Title: Pediatric Endocrine and Diabetes Patient Lists

Protocol Director: Darrell M. Wilson, MD

- 1. Explanation of the Study (What will happen to me in this study?)**— We will keep your name and some information about you in a database to help us manage your care and our clinic's operations. There are NO tests involved at all
- 2. Risks or Discomforts of Participating in the Study (Can anything bad happen to me?)** There are NO risks or discomforts.
- 3. Benefits of Participating in the Study (Can anything good happen to me?)**— We can send your parents letters about events they may be interested in.
- 4. Contact Information (Who can I talk to about the study?)**—You can contact Dr Wilson at 650 723 5791.
- 5. Voluntary Participation (What if I do not want to do this?)**—You can stop being in this study any time without getting in trouble and that your doctor will continue to treat you if treatment is necessary and available.

If you have any problems with this study, you may call the Institutional Review Board at (650) 723-5244 or write the Administrative Panel on Human Subjects in Medical Research, Administrative Panels Office, Stanford University, Stanford, CA 94305-5401. Anything you tell the IRB can be kept secret, if you want.

If you understand this study and are you willing to participate, please sign this form.

Signature of Child

Date