MyVHL: Patient Natural History Study

CONSENT FOR USE, DISCLOSURE AND / OR RELEASE OF PERSONAL AND HEALTH INFORMATION

Please complete this form electronically. Instructions for signing, saving, and submitting this form are on page 3.

PATIENT INFORMATION

Last Name | First Name / Middle Initial | Date of Birth (MM/DD/YY)

Street Address | City, State Zip | Country

Phone Number *(Include country code if outside of USA)* | E-mail

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PARENT / LEGAL GUARDIAN INFORMATION (if applicable)

Last Name | First Name / Middle Initial | Relationship to Patient

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I. AGENCY REQUESTING THE INFORMATION

The agency can request personal and health information for the patient listed above. The information to be released is described in Section III and IV below.

Agency: VHL Alliance
PO Box 844682
Boston, MA 02284-4682
USA

Agency Contact & Title:
Joshua Mann, MPH - Director of Health
josh.mann@vhl.org *//* 800-767-4845 x710

II. PHYSICIAN (PERSON) OR AGENCY PROVIDING THE INFORMATION

The person / agency may release my personal and health information for the patient listed above. The information to be released is described in Section III and IV below.

Person / Agency Name | Name of Office Contact Person

Street Address | Title of Contact Person

City, State, Zip | E-mail of Contact Person

Country | Phone of Contact Person

III. INFORMATION THAT MAY BE RELEASED

The people or agencies marked in Section IV below may view, copy, release, and exchange the information or records marked below. Please check all that apply to your needs now and in the future. This information may be shared verbally, in writing, and / or by email or fax.

- ☐ Medical Information, including by not limited to operative, emergency, radiology, consultations, progress notes
- ☐ Genetic Testing Results
- ☐ Speech / Language Information
- ☐ Rehabilitation Information
- ☐ Family Information, including by not limited to size of family, family income, family support
- ☐ Developmental Information
- ☐ Developmental Screening Information
- ☐ Other _____

The following information will not be released unless you specifically authorize it by marking the relevant box below:

- ☐ I specifically authorize the release of information pertaining to mental health diagnosis or treatment or psychological information (Welfare & Institutions Code, §§5328, et seq)

IV. APPLICABLE RECORDS

The records and imaging to be released may include (but are not limited to) the following:
By checking these boxes, you are indicating that the person / agency listed in Section II may be in possession of the indicated test results. This helps the VHL Alliance make sure that it is collecting all the relevant material that you have released.

- ☐ Genetic Testing Results
- ☐ Brain and/or Spine Scans
- ☐ Retina (Eye) Imaging
- ☐ Hearing Test Results
- ☐ Skin Biopsy Results
- ☐ Lung Testing and Scans
- ☐ Cardiovascular (Heart) Test Results
- ☐ Pheochromocytoma / Paraganglioma Test
- ☐ Kidney Test Results, Scans, Pathology
- ☐ Digestive System Test Results
- ☐ Thyroid / Parathyroid Test Results, Scans, and Pathology
- ☐ Other _____

V. INFORMATION MAY BE EXCHANGED BY THE FOLLOWING PERSONS / AGENCY(IES)

I know that my healthcare team includes the physicians and / or agencies marked below.
Again, this helps the VHL Alliance make sure all relevant material that you have released is collected. Please check all that apply to your needs now and in the future.

Healthcare services

- ☐ Primary Health Care
- ☐ Physician Specialist Provider
- ☐ Other _____

Social Services Agency

- ☐ Social Worker
- ☐ Case Manager
- ☐ Other _____

Mental Health Services

- ☐ Psychologist
- ☐ Physician / Psychiatrist
- ☐ Therapist
- ☐ Other _____

Part V continued from page 2.....

Family Resource and/or Regional Centers

- ☐ Case Manager
- ☐ Administrative Staff
- ☐ Family Support Worker

Other Agency:

VOLUNTARY: I know that I am not required to sign this consent form. I can refuse to sign this consent form, and it will not affect the services received from any of the agencies listed on this form.

LENGTH OF TIME: This consent will be valid from the date that I sign this form until the date marked in the box below.

If no date is entered, the form will be valid for one year after the date that I sign.

PURPOSE: The purpose of this patient information request is for medical research only.

WITHDRAWAL: I know that I can withdraw this consent at any time. To withdraw my consent, I must send a written note to the person or agency in Section I. The withdrawal will be valid as soon as the person or agency receives my note, but it will not apply to information that has already been shared after I signed the consent form.

SHARING OF INFORMATION: I know that my information may be shared more than once by the persons and/or agency(ies) in Sections I and II. The information may no longer be protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). It may still be protected by other State and Federal laws.

COPY: A copy of this consent form will be as good as the original. I know that I have a right to obtain a copy of this consent form if I ask for one.

ELECTRONIC SIGNATURE: By typing my full legal name and date in the specified boxes below, I attest to the best of my knowledge that the information on this form is true.

Electronic Signature of Patient

Date (MM/DD/YY)

Electronic Signature of Parent / Guardian (if applicable)

Date (MM/DD/YY)

PATIENT INSTRUCTIONS FOR SAVING & SUBMITTING THIS FORM:

1. Please save your completed and signed form, indicating the date it was signed in the file title:
YYYY.MM.DD - Patient's LastName, FirstName - release records from Person/Agency in Section II for MyVHL example: *2016.11.04 - Doe, Jane - release records from Dr Jones for MyVHL*

2. Please email your form to Josh Mann: Josh.Mann@vhl.org
Email Subject: (**same as the form file name**)