Children's Hospital of Philadelphia℠

LAB-1511
Rev. 3/23

LAST NAME | FIRST NAME

MR# | DOB

PLACE PATIENT LABEL HERE *OR* COMPLETE ABOVE

DO NOT HANDWRITE PATIENT INFORMATION HERE

Division of Genomic Diagnostics
FAMILY MEMBER TEST REQUISITION AND CONSENT FOR PROBAND EXOME ANALYSIS INTERPRETATION

SHIP TO: Children's Hospital of Philadelphia, Genomic Diagnostics Laboratory, 3615 Civic Center Blvd., Abramson Research Center, 714J, Philadelphia, PA 19104-4302 - Phone: (267) 426-1447

FAMILY MEMBER SPECIMEN INFORMATION

Name: (Last, First, Middle) _____ MR# _____

Sex: ☐ Male ☐ Female ☐ Unknown ☐ Other: _____

Date of Birth: (Month/Day/Year) _____ Phone Number: _____

Address: _____
Street *City* *State* *Zip* *Country*

Race/Ethnicity: (Check all that apply) ☐ Amish ☐ Asian ☐ Black/African-American ☐ Caucasian ☐ East Indian ☐ French Canadian ☐ Hispanic ☐ Jewish-Ashkenazi ☐ Jewish-Sephardic ☐ Mediterranean ☐ Native American ☐ Other: _____

Specimen Type: ☐ *DNA >15 μg Specify Tissue of Origin: _____
☐ Peripheral Blood in EDTA tube > 3 mL ☐ Saliva (Contact lab for kits) ☐ Other: _____
* Nucleic acids (DNA or RNA) must be extracted from a CAP or CLIA certified laboratory.

If interested in sending a specimen other than blood, saliva, or DNA, please call the lab to discuss.

Collection Date: (Month/Day/Year) _____ Collection Time: _____ AM/PM

Family Member Test Requested to aid in proband exome analysis:
☐ Exome *(Please complete consent below.)*
☐ Exome Reanalysis *(A new consent form is **required** for family members who originally provided consent **prior to 12/8/2020** or who want secondary findings.)*
☐ Sanger Confirmation Only

EXOME ANALYSIS CONSENT FORM (FAMILY MEMBER)

I understand that my sample is being tested to help understand the exome analysis results of

_____.
Name of primary patient/proband

A healthcare provider has explained the test and its limitations to me. I understand that I will not automatically receive a separate results report. However, the patient's report may include information about me. This information may include:

1) Findings in me that are related to the patient's reason for testing,
2) Secondary findings in me that are first found in the patient, if I select Option 1 below,
3) Incidental findings (unrelated to the patient's reason for testing) in me that are first found in the patient, if I select Option 1 below.

STORAGE AND USE OF INFORMATION AND SAMPLES

- I understand that the lab will keep my genetic data/information for at least two years, as per professional and regulatory guidelines. There is no guarantee that my samples will be available or usable for additional or future testing.
- I understand that the laboratory may perform reanalysis of the patient's exome data, as well as the data of the family members who were tested. Reanalysis may be requested by a healthcare provider as a part of future care. A new consent form may not be requested if provider reanalysis is ordered by the patient's provider. In addition, although not performed routinely, the laboratory may independently initiate limited reanalysis of a patient's (and any submitted family members') exome data for internal purposes, such as quality improvement. The laboratory may share new relevant information from the laboratory-initiated reanalysis with the patient's healthcare providers. Please discuss with the patient's healthcare provider about receiving any updated information.
- Samples and raw genetic data relating to me without identifiers, such as name and date of birth, may be maintained in CHOP-based databases and may be shared with external genetic databases that are not located at, owned by, or operated by CHOP. These databases were created to improve our interpretation of genetic results and ensure that clinical genetic laboratories are interpreting results in the same way. The information contained in these databases may be used for research purposes.
- In rare instances, CHOP may ask external (non-CHOP) clinical laboratories to perform all or part of the exome test. The external laboratory may keep copies of this genetic information, including raw genetic data and/or results reports.

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CHOICE FOR SECONDARY AND INCIDENTAL FINDINGS

Please Note: the laboratory will only look for the secondary and other findings unrelated to the patient's reason for testing in you if you select Option 1 below. (The laboratory's practices for looking for secondary and other unrelated findings are described in the Proband Exome Requisition and Consent form.)

Please initial one of the options below regarding your choice for secondary findings. (The adult family member or a parent/guardian of a minor child must initial next to the selected option.)

_____ ***(initial)*** **Option 1:** If secondary or incidental findings (unrelated to the patient's reason for testing) are identified and reported in the patient (proband), **I choose to have the laboratory look for and report these findings in me.** I understand that the absence of findings does not rule out these conditions. This test will not find all variants in these genes.

Note: ***Secondary*** and ***incidental findings*** are results that are not clearly related to the patient's reason for testing. These findings may lead to serious health problems that can be improved or avoided when monitored or treated. Therefore, they are considered ***medically actionable***. The laboratory can purposefully look for these findings as a part of the test (if selected here). Unrelated findings that are non-medically actionable will generally not be reported; however, there are rare exceptions.

_____ ***(initial)*** **Option 2:** If secondary or incidental findings (unrelated to the patient's reason for testing) are identified and reported in the patient (proband), **I DO NOT want the laboratory to look for or report these findings in me.** I am aware that I will not have direct access to these results later, although I may be able to pursue separate testing if desired.

By signing this document, you are agreeing that the test, its limitations, and use and retention of related data and samples have been explained to you, and you consent and agree to the test and these uses.

Family Member Statement: I acknowledge that I have discussed the benefits, risks, and limitations of exome analysis with my healthcare providers. I consent to the test.

Family Member Signature	Printed Name	Date	Time
Parent/Legal Guardian if Different from Family Member Signature	Printed Name	Date	Time

Healthcare Provider's Statement: I explained the benefits, risks, limitations, and data use and retention of exome analysis to this individual and addressed his/her questions about the test. I understand that it is my responsibility to interpret the clinical relevance of the results for this individual and to provide appropriate follow-up recommendations.

Healthcare Provider Signature	Printed Name / and Contact Number	Date	Time
Interpreter Signature / Witness Signature (Circle Relevant Role)	Printed Name	Date	Time

Phone: (267) 426-1447; Fax: (215) 590-3514; DGDGeneticCounselor@chop.edu; www.chop.edu/centers-programs/division-genomic-diagnostics

*Testing will not be initiated until all necessary samples and clinical information are submitted to the laboratory. Send pertinent medical records with this form.

Our Commitment to Diverse Populations

The Children's Hospital of Philadelphia complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. The Children's Hospital of Philadelphia does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

The Children's Hospital of Philadelphia:

- Provides free aids and services to people with disabilities to communicate effectively with us, such as:
    - Qualified sign language interpreters
    - Written information in other formats (large print, audio, accessible electronic formats, other formats)

- Provides free language services to people whose primary language is not English, such as:
    - Qualified interpreters
    - Information written in other languages

If you need these services, contact 1-800-879-2467.

If you believe that Children's Hospital of Philadelphia has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with: The Family Relations Office, 3401 Civic Center Blvd, Philadelphia, PA 19104, Phone: 267-426-6983, Fax: 267-426-7412, Email: familyrelations@email.chop.edu
You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Family Relations is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at https://ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue
SW Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)
Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html

October 2016

CHOP is Committed to Language Accessibility

If you speak another language, assistance services, free of charge, are available to you.

Español-Spanish ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-879-2467.

繁體中文–Chinese 注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 1-800-879-2467。

العربية -Arabic ملحوظة: إذا كنت تتحدث اللغة العربية فإن خدمات المساعدة اللغوية تتوفر لك بالمجان- اتصل بالرقم 1-800-879-2467.

Tiếng Việt-Vietnamese CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-800-879-2467.

Français-French ATTENTION: Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-800-879-2467.

Português-Portuguese ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1-800-879-2467.

नेपाली-Nepali ध्यान दिनुहोस्: तपाईंले नेपाली बोल्नुहुन्छ भने तपाईंको निम्ति भाषा सहायता सेवाहरू निःशुल्क रूपमा उपलब्ध छ । फोन गर्नुहोस् 1-800-879-2467 ।

ខ្មែរ-Cambodian ប្រយ័ត្ន៖ បើសិនជាអ្នកនិយាយ ភាសាខ្មែរ, សេវាជំនួយផ្នែកភាសា ដោយមិនគិតឈ្នួល គឺអាចមានសំរាប់បំរើអ្នក។ ចូរទូរស័ព្ទ 1-800-879-2467។

বাংলা-Bengali লক্ষ্য করুনঃ যদি আপনি বাংলা, কথা বলতে পারেন, তাহলে নিঃখরচায় ভাষা সহায়তা পরিষেবা উপলব্ধ আছে। ফোন করুন ১-800-879-2467।

Русский-Russian ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-800-879-2467.

한국어-Korean 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-800-879-2467 번으로 전화해 주십시오.

Bahasa Indonesia-Indonesian PERHATIAN: Jika Anda berbicara dalam Bahasa Indonesia, layanan bantuan bahasa akan tersedia secara gratis. Hubungi 1-800-879-2467.

اُردُو -Urdu خبردار: اگر آپ اردو بولتے ہیں، تو آپ کو زبان کی مدد کی خدمات مفت میں دستیاب ہیں ۔ کال کریں 1-800-879-2467 .

Türkçe-Turkish DİKKAT: Eğer Türkçe konuşuyor iseniz, dil yardımı hizmetlerinden ücretsiz olarak yararlanabilirsiniz. 1-800-879-2467 irtibat numaralarını arayın.

Polski-Polish UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 1-800-879-2467.

Italiano-Italian ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 1-800-879-2467.

हिंदी-Hindi ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-800-879-2467 पर कॉल करें।

ગુજરાતી-Gujarati સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-800-879-2467.

Tagalog-Tagalog-Filipino PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-800-879-2467.

日本語 -Japanese 注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。1-800-879-2467 まで、お電話にてご連絡ください。

Deutsch-German ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-800-879-2467.

Deitsch-Pennsylvania Dutch Wann du Deitsch (Pennsylvania German / Dutch) schwetzscht, kannscht du mitaus Koschte ebber gricke, ass dihr helft mit die englisch Schprooch. Ruf selli Nummer uff: 1-800-879-2467.