

**CONSENT AND HIPAA AUTHORIZATION FOR THE RELEASE OF  
PROTECTED HEALTH INFORMATION**

**Emory University, Inc.  
School of Medicine  
Department of Human Genetics  
JScreen Program**

1. Patient Name: \_\_\_\_\_ (referred to as “You” or “Your”)
2. Address: \_\_\_\_\_
3. Date of Birth: \_\_\_\_\_
4. Telephone: \_\_\_\_\_
5. Email address: \_\_\_\_\_
6. **Confidentiality and HIPAA Authorization to use and disclose Health Information**
  - a. Any information obtained as a result of Your participation in the Emory University, Inc. School of Medicine Department of Human Genetics (“Emory”) JScreen Program (“JScreen”) will be kept as confidential as legally possible. A copy of this signed Authorization form will be retained by JScreen and will be subject to JScreen’s and Emory’s confidentiality policies. Nevertheless, Federal laws require that Your privacy and security be protected and unauthorized access to Your health information be prevented.
  - b. Emory and others need to make certain uses and disclosures of Your Health Information (as defined below) in order to provide you with services and to administer the JScreen Program. Therefore, You agree to permit the agents and subcontractors of Emory, JScreen, the testing laboratories, and your personal health care providers (when applicable) (together “Providers”) to use and disclose Health Information about You as described below.
  - c. The health information about You (the “Health Information”) that may be used and disclosed includes:
    - i. All information collected in connection with the JScreen Program described in this Authorization Form, including without limitation, Individually Identifiable Health Information and Protected Health Information as defined by HIPAA; and,
    - ii. Individually Identifiable Information that can identify you, including, but not limited to Your initials, name, birth date and address; and,
    - iii. Health and medical information collected in connection with Your participation in the JScreen Program, including, but not limited to the following: a) Your entire medical chart; including without limitation, your genetic test results and other genetic information about You and genetic counseling information; b) health information received from Your other doctors’ offices or clinics; c) reports from Your laboratory or other tests or x-rays; d) Your medical history; e) if applicable, the physical exam conducted by the ordering physician; f) reports from other procedures and g) any images or videos of You obtained with Your knowledge for purposes of the JScreen Program.
  - d. The Providers may use, disclose, access and transmit Health Information in Your medical records:

- i. Among themselves and with other healthcare providers participating in or providing services relating to the JScreen Program; and,
  - ii. To Your insurance carrier or third party payors (if applicable); and,
  - iii. To Your Email address; and,
  - iv. If applicable, to Your partner, spouse or domestic partner, and other at risk family members; and,
  - v. To other genetic counselors or physicians as referred by the JScreen Program. Your genetic counselors and physicians are authorized to provide information back to the JScreen Program documenting the outcome of referral.
- e. Nature and Purpose of Disclosure.
  - i. Your Health Information may be released for the purposes of Your participation in the JScreen Program, which includes genetic testing, data collection and as otherwise described in this Authorization.
  - ii. The purpose for releasing Your genetic test results is to provide You with genetic counseling services and review by the ordering healthcare provider.
  - iii. Other purposes of the uses and disclosures described in this authorization are for the management, evaluation, reporting, outreach and marketing of the JScreen Program and may be released to additional parties, which may include, but is not limited to, funding sources, partner organizations, and vendors. This data may include de-identified aggregate tracking of the statistics such as dates of service, demographics (e.g., age, state of residence, gender, pregnancy status), total number of individuals screened, number of carriers, number of carrier couples, number of affected individuals with various diseases, and percentage of people with health insurance.
- f. Publication.
  - i. You grant JScreen and Emory permission to use and/or disclose Your Health Information as de-identified aggregated data in publications or in any other broadcast, print or electronic media, including without limitation newspaper, radio, television, magazine, Internet, or computer transmission. You waive any right to inspect or approve Your depictions in these works.
- g. Re-Disclosure.
  - i. You understand that if Your Health Information is disclosed to a third party who is not required to abide by the federal, state and local medical privacy laws, the media or the general public pursuant to this authorization, it may no longer be protected by those laws and may be subject to redisclosure. You further understand that once such materials are in the possession of the media or members of the general public, JScreen and Emory do not retain control over their editing or use.
- h. Expiration of Authorization.
  - i. Unless You request in writing to revoke Your authorization, You understand that this authorization will be effective until 10 years after closure of the JScreen Program.
- i. Right to Revoke Authorization
  - i. You understand that You have a right to revoke this authorization at any time. You understand that if You wish to revoke this authorization, You must do so in writing and present Your written revocation to Emory University, Inc., School of Medicine, Department of Human Genetics, JScreen Program at 5115 New Peachtree Rd., Suite 301, Atlanta, GA 30341. You further understand that the

revocation will not apply to any Health Information that has already been released in reliance on this authorization. For example, a revocation will not apply to any Health Information that has already been disclosed pursuant to this authorization but will prevent any future disclosures.

- j. Refusal to Authorize Use and Disclosure.
  - i. You understand that this authorization is voluntary and that Your refusal to sign this authorization permitting certain uses and disclosures of Your Health Information will in no way affect Your eligibility to receive medical care at any Emory health care facility. However, Emory may still use and disclose Your Health Information without Your authorization as permitted by law for certain limited reasons, such as providing You with genetic counseling and releasing Your de-identified information.
- k. **Release of Genetic Testing Information.** The Genetic Information Non-Discrimination Act (“GINA”) is a federal law that prohibits discrimination in health coverage and employment based on genetic information of individuals. GINA, together with already existing non-discrimination provisions of the federal Health Insurance Portability and Accountability Act, generally prohibits health insurers or health plan administrators from requesting or requiring genetic information of an individual or an individual’s family members, or using such information for decisions regarding coverage, rates, or pre-existing conditions. GINA also prohibits employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment. The following is a brief description of the coverage and limitations of the GINA statute:
  - i. GINA discrimination protections apply to health insurance coverage and employment decisions only.
  - ii. GINA’s provisions prohibiting discrimination in health coverage based on genetic information do not extend to protect decisions made by companies or entities regarding the availability to any applicant for life insurance, disability insurance or long term care insurance.
  - iii. GINA discrimination protections in employment on the basis of genetic information do not apply to employers with fewer than 15 employees.
- l. You consent to and authorize release of your genetic testing information to your insurance company and your other third party payors (if applicable).
- m. Release and Waiver
  - i. If the Health Information You have authorized JScreen and Emory to disclose contains any privileged psychiatric or psychological information related to the treatment of physical and/or mental illness, chemical dependency or alcohol abuse, or testing or treatment of any communicable or infectious disease such as acquired immunodeficiency syndrome (AIDS), Immunodeficiency Syndrome Related Complex (ARC), human immunodeficiency virus (HIV), Venereal Disease, Tuberculosis, or Hepatitis, You hereby waive any privilege concerning such information for the purposes authorized above. You hereby release the JScreen and Emory and its affiliated entities, including but not limited to Emory Healthcare, Inc., Emory University Hospital, Emory University Hospital Midtown, Emory Orthopaedics & Spine Hospital, Emory Johns Creek Hospital, Saint Joseph’s Hospital of Atlanta, Inc., , The Emory Clinic, Emory-Children’s Center, and the Wesley Woods Center), and each of their trustees, officers, employees and agents, from any and all claims, liability, and damages, which might arise from the use and/or disclosure of Your Health Information.

\_\_\_\_\_  
Signature of Patient (or Patient’s Representative)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Time

Printed Name \_\_\_\_\_

Description of Authority to Act for Patient \_\_\_\_\_

NOTE: A COPY OF THIS COMPLETED, SIGNED AND DATED FORM MUST BE PROVIDED TO THE PATIENT AND/OR PATIENT'S REPRESENTATIVE AND A COPY MUST BE PLACED IN THE PATIENT'S MEDICAL RECORD.