



Carrier Screening Program Registration

Use this form to register for the carrier screening program. Please complete this form electronically. If you sign the form electronically, you may send it back using the Submit button at the end of the form. If you sign by hand, please print, scan, and sign the form, and then email the scan to us at GeneticScreening@juf.org. After you register and complete the pre-screening education, you will receive a second form to register for the actual test with our collaborating medical provider, Insight Medical Genetics.

I. Basic Information

Name:						
Primary Phone:		Email:				
Street Address:						
City:		State:		Zip:		
Date of Birth			Sex			

Note: You must be in Illinois to participate in this program. If you are out of state, please contact the Center for assistance locating a screening resource in your area.

Please consider joining the Center's mailing list to receive additional information and updates from the Center as well, including its newsletter, event announcements, and other periodic communications. Select "Add Me" to join the list, or "Do Not Add Me" to decline. If you join the list, you may opt out at any time.

Is your spouse or partner also participating in this program? (If yes, they must register separately.)

If yes, please provide the full name of your spouse or partner.

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How did you hear about the Norton & Elaine Sarnoff Center for Jewish Genetics? Check all that apply.

- | | |
|--------------------------------------------------------|-------------------------------------------------------------|
| <input type="checkbox"/> Center website | <input type="checkbox"/> Friend or Family Member |
| <input type="checkbox"/> Center newsletter | <input type="checkbox"/> Online Search Engine |
| <input type="checkbox"/> Center event | <input type="checkbox"/> Google Ad |
| <input type="checkbox"/> Center flyer | |
| <input type="checkbox"/> Facebook | <input type="checkbox"/> Doctor/Physician: |
| <input type="checkbox"/> Twitter | <input type="checkbox"/> Synagogue, Rabbi, or Other Clergy: |
| <input type="checkbox"/> JUF website or JUF News | <input type="checkbox"/> Other (specify): |
| <input type="checkbox"/> JUF Young Leadership Division | |

II. Demographic Information

A. Required Questions

Are you of Jewish descent (i.e. do you have at least one parent, grandparent, or great grandparent of Jewish descent)?

Is your partner of Jewish descent (i.e. does he/she have at least one parent, grandparent, or great grandparent of Jewish descent)?

B. Optional Questions

Please answer these questions to help us better understand the population we serve. Your answers will not be connected to your individual records, and will not have any impact on requests for patient assistance.

If you identify as Jewish, what is your denomination?

What is your current relationship status?

What is the highest level of education you have completed?

Are you a health care professional or work in a biological sciences field?

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What category best describes your annual household income?

What best describes the area you live in?

If you have medical insurance, what kind of insurance do you have?

III. Consent & Acknowledgement

I understand that I am a participant in a Jewish genetic disorders program presented by Jewish Federation of Metropolitan Chicago (JF), Jewish United Fund of Metropolitan Chicago (JUF), Center for Jewish Genetics (Center) and Insight Medical Genetics (Insight). The program includes information about and testing for 83 autosomal recessive disorders and in some cases, for Fragile X. I understand that my participation in the program, including an educational survey, and/or testing is purely voluntary on my part, that I have no obligation to participate in the program or be tested, and that if I wish to obtain information on these disorders or be tested through another service, I may use any health care provider of my own choosing at my expense.

I further understand that Insight is the sole provider of the program information and that Insight or its agents or employees will administer the tests, process the specimens and analyze and report the test results. Therefore, I understand that neither JF, JUF, the Center nor any agency affiliated with JF or JUF is responsible for the content or accuracy of the program information, for any risk I undertake in submitting to testing or for the accuracy of test results. I realize that if I have questions or concerns about these disorders, whether to be tested or test results, I should discuss those matters with my personal physician.

I hereby release JF, JUF, the Center and all agencies affiliated with JF or JUF from all liability arising out of or in any way connected with my participation in the program, including the survey and/or the testing in which I participate.

I have received a copy of the Center's Privacy Notice (attached to this form).

Name:		Date:	
Signature:			
If your PDF reader supports it, you may sign this form electronically.			

By providing your consent for screening, you agree to be contacted by the Center as needed to facilitate your screening process, including post-screening follow-up and evaluation surveys.

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IV. Program Fee

Select one:

Please provide a credit card for the program fee.

Name on Card:					
Card Type:		Card Number:			
Security Code:		Expiration Date:		Billing Zip Code	

V. Instructions to Return Form

Please choose one method to return the form.

If you did <u>not</u> sign electronically	If you signed electronically
<p style="text-align: center;">Option 1</p> <p>Print, sign, and scan the form. E-mail the scanned form to GeneticScreening@juf.org.</p>	<p style="text-align: center;">Option 2</p> <p>Click the submit button below and the contents of the form will be e-mailed.</p> <p style="text-align: center;">SUBMIT</p>

Center For Jewish Genetic Disorders

Notice of Privacy Practices Regarding Protected Health Information

Effective Date: September 19, 2016

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

At the Center for Jewish Genetic Disorders, we respect your privacy and will protect your health information responsibly and professionally in compliance with the Health Insurance Portability And Accountability Act of 1996 (“HIPAA”) and its rules, as well as the Health Information Technology for Economic and Clinical Health Act (“HITECH Act”) and the HITECH Act Final Rule of 2013 which amended HIPAA. We’re required to maintain the privacy of your health information and to provide you with this Notice of Privacy Practices (“Notice”). Also, we’re required to abide by the terms of the Notice that’s currently in effect. We reserve the right to change the terms of this Notice and to make the new Notice provisions effective for all PHI we maintain. If we change this Notice, the revised Notice will be posted in our offices, and on our website (<https://www.jewishgenetics.org/>), or a copy of the revised Notice will be mailed to you.

This notice applies to all individuals seeking services of the Center for Jewish Genetic Disorders. It describes how we may collect, use, and disclose your health information. It also describes your rights concerning your health information.

State and federal laws require us to: maintain the privacy of your health information; provide you with this Notice about its legal duties and privacy practices and your legal rights pertaining to health information we collect and maintain about you; to notify you following a breach of unsecured protected health information; follow the privacy practices described in this Notice while it is in effect; notify you if we are unable to agree to a requested restriction pertaining to your health information; and accommodate reasonable requests you may have to communicate health information by alternative means or at alternative locations.

As you read this Notice, you’ll see an important term: “**protected health information**” or **PHI**. PHI is information about you, including health and demographic information created and received by us that can reasonably be used to identify you. PHI includes information that relates to your past, present, and future physical or mental condition, the provision of health care, and payment for that care.

How We Use or Share Protected Health Information (PHI)

Below are some examples of ways we may use or share information about you without your consent or authorization. We use and disclose health information about you for treatment, payment, healthcare operations, and for other purposes. There are also State and federal laws that may require or allow us to release your health information to others. We may use or share your PHI as follows:

Treatment: We may disclose health information about you to physicians, hospitals, medical technicians or other healthcare providers who are or who may be providing treatment to you.

Payment: We may use and disclose your health information to obtain payment for services we provide to you.

Health Oversight Activities: We may disclose your PHI to a government agency authorized to oversee the health care system or government programs, or its contractors (*e.g.*, state insurance department, U.S. Department of Labor) for activities authorized by law, such as audits, examinations, investigations, inspections and licensure activities.

Legal Proceedings: We may disclose your PHI in response to a court or administrative order, subpoena, discovery request, or other lawful process, under certain circumstances.

Law Enforcement: We may disclose your PHI to law enforcement officials under limited circumstances. For example, in response to a warrant or subpoena, or for the purpose of identifying or locating a suspect, witness, or missing person, or to provide information concerning victims of crimes.

For Public Health Activities: We may disclose your PHI to a government agency that oversees the health care system or government programs for activities such as preventing or controlling disease or activities related to the quality, safety, or effectiveness of an FDA regulated product or activity.

Required by Law: We may disclose your PHI when we're required to do so by law.

Workers' Compensation: We may disclose your PHI when required by workers' compensation laws.

Victims of Abuse, Neglect, or Domestic Violence: We may disclose your PHI to appropriate authorities if we reasonably believe that you're a possible victim of abuse, neglect, domestic violence or other crimes.

Coroners, Funeral Directors, and Organ Donation: In certain instances, we may disclose your PHI to coroners or funeral directors, and in connection with organ donation.

Research: We may disclose your PHI to researchers, if certain established steps are taken to protect your privacy.

Threat to Health or Safety: We may disclose your PHI to the extent necessary to avert a serious and imminent threat to your health or safety or the health or safety of others.

For Specialized Government Functions: We may disclose your PHI in certain circumstances or situations to a correctional institution if you are an inmate in a correctional facility, to an authorized federal official when it's required for lawful intelligence or other national security activities, or to an authorized authority of the Armed Forces.

For Cadaveric Organ, Eye, or Tissue Donation: We may disclose your PHI for the purpose of facilitating organ, eye, or tissue donation and transplantation.

Appointment Reminders: We may use and disclose health information to contact you as a reminder that you are scheduled for further treatment or medical care.

Business Associates: We may use and disclose certain health information about you to business associates. A business associate is an individual or entity that works with the organization to perform or assist the organization in a function or activity, which necessitates the use or disclosure of health information. Examples of business associates include, but are not limited to, the medical director, consultants, lawyers, and third party billing companies. We require all our business associates to protect the confidentiality of your health information.

Fundraising: We may use your demographic information to contact you in an effort to raise funds for the organization. You have a right to opt out of receiving fundraising communications. If you choose not to receive these fundraising communications, we must provide you with a clear and conspicuous opportunity to elect not to receive any further fundraising communications and we may not condition treatment or payment on your choice with respect to the receipt of fundraising communications. We may not make fundraising communications to you if you have elected to opt out of receiving these communications, but we may provide you with a method to opt back in to receive these communications.

To Provide You Notice of Breaches of Unsecured PHI: We may contact you to provide you with any notice of any breach of your unsecured PHI.

Before we can use or disclose your PHI for any reason other than those listed in this section titled “How We Use or Share Protected Health Information (PHI)”, we are required to obtain your written authorization. For example, a specific authorization will be required for use or disclosure of your PHI 1) if it involves certain psychotherapy notes, 2) for marketing (except if the communication is face-to-face, or is for a promotional gift of nominal value) or for any marketing that involves financial remuneration; or 3) for any sale of your PHI. You may revoke the authorization at any time as long as you do so in writing. Information provided as a result of your authorization will no longer be provided once you revoke the authorization. Your revocation may not be effective in certain situations where we have already taken action in reliance on your authorization.

Genetic Information Limitations: Under the Genetic Information Nondiscrimination Act of 2008 (“GINA”), group health plans, health plan insurers, or health plan clearinghouses cannot base eligibility, benefits, or premiums on genetic information. Health plans and insurers are prohibited from requesting or requiring an individual or group of individuals to undergo genetic services or genetic tests. GINA also prohibits the collecting of genetic information (including family medical history) in connection with the enrollment or underwriting process. We will not use or disclose genetic information of an individual for underwriting purposes.

What Are Your Rights

You have the following rights regarding the protected health information (“PHI”) we maintain about you.

You have the right to ask us to restrict our use and disclosure of PHI for the purposes of treatment, payment or health care operations. This includes uses and disclosures to family members, relatives, close personal friends, or other persons identified by you who may be involved with your care or payment for your care. We’ll consider your request, but we aren’t required to agree to restrict the information. You also have a right to request a restriction on disclosures to us if you pay out of pocket in full for any services provided by your health care providers.

You have the right to ask to receive confidential communications. You may request that when we send communications to you that contain PHI, we send them to you by alternative means or to an alternative location. You must request this in writing and clearly state that our disclosure of all or part of that communication could endanger you. You must also tell us the alternative location (*e.g.*, fax number, address, etc.) to which you would like us to send the information.

You have the right to inspect and obtain a copy of the PHI that we maintain about you in a designated record set. A designated record set contains PHI that we collect, maintain or use to administer or make decisions regarding your enrollment, payment, claims adjudication, or case/medical management. If we don’t maintain the PHI, but we know who does, we’ll tell you. Requests to access the information must be made in writing, and we’ll respond within 30 days of receipt of your request. We may charge a reasonable, cost-based fee to provide you with the information. There are exceptions as to what information can be accessed. For example, information compiled for legal proceedings cannot be accessed. If we deny access to your information, in part or in whole, we will notify you in writing. Our denial will include the reason for the denial, your review rights (if applicable), and information on how to file a complaint.

You have the right to ask us to amend protected health information about you that’s contained in a designated record set (as described above). All amendment requests must be in writing and include a reason for the request. We’ll respond within 60 days of receiving the request. If the request is approved, we’ll amend the information in our records and notify any other individual(s) whom we know and/or whom you have told us have received the information, and we’ll provide them with the amendment as well. In certain cases, your request may be denied. For example, we may deny a request if the information we have on file is accurate or if we didn’t create the information. We’ll notify you in writing of any denial. You may respond by filing a written statement of disagreement with us, and we have the right to rebut the disagreement statement. Should this occur, you have the right to request that your original request, our denial, and any statement of disagreement, along with our rebuttal, be included in future disclosures of the PHI.

You have the right to request an accounting of certain disclosures of protected health information. An accounting will show you to whom we provided your PHI. The first accounting request in a 12-month period of time will be provided free of charge. Subsequent requests are subject to a reasonable, cost-based fee, of which you will be made aware of in advance. All requests for disclosures must be made in writing, and we’ll respond within 60 days of receipt. There are some accountings we aren’t required to provide. For example, we aren’t required to

account for disclosures made for purposes of treatment, payment, or health care operations. Also, we won't provide accountings for disclosures that you have authorized, and certain other disclosures such as for national security purposes.

You have the right to a paper copy of this notice upon request. You may write us at the address provided in the Complaints and Inquiries section of this notice, or call us and we'll mail or fax a current notice to you.

For more information, or to begin the formal process connected with these rights, please contact the Privacy Officer, Jason Rothstein, at the Center for Jewish Genetic Disorders, 30 S. Wells Street, Chicago, IL 60606, Phone (312) 357-4718, Fax (312) 855-2477.

Complaints and Inquiries

You may register a complaint to us or to the Secretary of the U.S. Department of Health and Human Services ("DHHS") if you believe that your privacy rights have been violated. To file a complaint with us, please submit it in writing and address it to:

Jason Rothstein
Privacy Officer
Center for Jewish Genetic Disorders
30 S. Wells Street
Chicago, IL 60606
Phone (312) 357-4718
Fax (312) 855-2477

You also may send a complaint to the DHHS. Further information may be found at:
<http://www.hhs.gov/ocr/privacy/hipaa/complaints/index.html>.

We support your right to protect the privacy of your medical information. You will not face any retaliation if you file a complaint. If you request additional information regarding our Notice please contact our Privacy Officer listed above.

Please note: You won't be retaliated against or be denied any benefit or service because you file a complaint.