

<<First Name>> <<Last Name>> <<Address1>> <<Address2>> <<City>>, <<State>> <<Zip>>>

30776

Enrollment Code: <<**XXXXXXXX**>>

To Enroll, Scan the QR Code Below:



Or Visit:

https://app.idx.us/account-creation/protect

October 12, 2023

Incident Notice

Dear <<First Name>> <<Last Name>>,

National Organization for Rare Disorders, Inc. ("NORD") is writing to notify you regarding potential unauthorized access to or acquisition of your personal information (the "Incident"). We have not found any evidence that your information was misused as a result of the Incident. However, out of an abundance of caution, and in accordance with applicable law, we are providing you this notice so that you can take steps to minimize the risk that your information will be misused. The attached sheet describes steps you can take to protect your identity, credit, and personal information.

Under Massachusetts law, you have the right to obtain any police report filed in connection with this Incident. If you are the victim of identity theft, you also have the right to file a police report and obtain a copy of it.

You may also place a security freeze on your credit reports, free of charge. A security freeze prohibits a credit reporting agency from releasing any information from a consumer's credit report without written authorization. However, please be aware that placing a security freeze on your credit report may delay, interfere with, or prevent the timely approval of any requests you make for new loans, credit mortgages, employment, housing, or other services. Under federal law, you cannot be charged to place, lift, or remove a security freeze. You must place your request for a freeze with each of the three major consumer reporting agencies: Equifax, Experian, and TransUnion. To place a security freeze on your credit report, you may send a written request by regular, certified, or overnight mail at the addresses below. You may also place a security freeze through each of the consumer reporting agencies' websites or over the phone, using the contact information below:

Equifax Security Freeze, P.O. Box 105788, Atlanta, GA 30348 1-800-349-9960 https://www.equifax.com/personal/credit-report-services/

Experian Security Freeze, P.O. Box 9554, Allen, TX 75013 1-888-397-3742 https://www.experian.com/freeze/center.html

1779 MASSACHUSETTS AVENUE NW, SUITE 500 WASHINGTON, DC 20036 T 202-588-5700 • F 202-588-5701

7 KENOSIA AVENUE DANBURY, CT 06810 T 203-744-0100 ■ F 203-263-9938 1900 CROWN COLONY DRIVE, SUITE 310 QUINCY, MA 02169 T 617-249-7300 ■ F 617-249-7301 TransUnion Security Freeze, P.O. Box 160, Woodlyn, PA 19094 1-888-909-8872

https://www.transunion.com/credit-freeze

To request a security freeze, you will need to provide some or all of the following information to the credit reporting agency, depending on whether you do so online, by phone, or by mail:

- 1. Your full name (including middle initial as well as Jr., Sr., II, III, etc.);
- 2. Social Security number;
- 3. Date of birth:
- 4. If you have moved in the past five (5) years, the addresses where you have lived over the prior five years;
- 5. Proof of current address, such as a current utility bill, telephone bill, rental agreement, or deed;
- 6. A legible photocopy of a government issued identification card (state driver's license or ID card, military identification, etc.);
- 7. Social Security Card, pay stub, or W-2;
- 8. If you are a victim of identity theft, include a copy of either the police report, investigative report, or complaint to a law enforcement agency concerning identity theft.

The credit reporting agencies have one (1) to three (3) business days after receiving your request to place a security freeze on your credit report, based upon the method of your request. The credit bureaus must also send written confirmation to you within five (5) business days and provide you with a unique personal identification number (PIN) or password (or both) that can be used by you to authorize the removal or lifting of the security freeze. It is important to maintain this PIN/password in a secure place, as you will need it to lift or remove the security freeze.

To lift the security freeze in order to allow a specific entity or individual access to your credit report, you must make a request to each of the credit reporting agencies by mail, through their website, or by phone (using the contact information above). You must provide proper identification (including name, address, and social security number) and the PIN number or password provided to you when you placed the security freeze, as well as the identities of those entities or individuals you would like to receive your credit report. You may also temporarily lift a security freeze for a specified period of time rather than for a specific entity or individual, using the same contact information above. The credit bureaus have between one (1) hour (for requests made online) and three (3) business days (for requests made by mail) after receiving your request to lift the security freeze for those identified entities or for the specified period of time.

To remove the security freeze, you must make a request to each of the credit reporting agencies by mail, through their website, or by phone (using the contact information above). You must provide proper identification (name, address, and social security number) and the PIN number or password provided to you when you placed the security freeze. The credit bureaus have between one (1) hour (for requests made online) and three (3) business days (for requests made by mail) after receiving your request to remove the security freeze.

In addition, we are offering identity theft protection services through IDX, A ZeroFox Company, the data breach and recovery services expert. IDX identity protection services include: 24 months of Credit and CyberScan monitoring, a \$1,000,000 insurance reimbursement policy, and fully managed id theft recovery services. With this protection, IDX will help you resolve issues if your identity is compromised.

We encourage you to enroll in free IDX identity protection services by going to https://app.idx.us/accountcreation/protect, calling 1-800-939-4170, or scanning the QR image and using the Enrollment Code provided above. IDX representatives are available Monday through Friday from 6 am - 6 pm Pacific Time. Please note the deadline to enroll is January 1, 2024.

We sincerely apologize for any concern or inconvenience this Incident causes. We are committed to maintaining the security and privacy of the personal information entrusted to us. To that end, we have, since the Incident, taken numerous steps to further secure our systems and information.

We understand that you may have questions about this incident that are not addressed in this letter. If you have additional questions, please call me at 203-304-7219, Monday through Friday from 9:00 a.m. to 5:00 p.m.

Sincerely,

Norine Schwarzchild Vice President of Human Resources National Organization for Rare Disorders, Inc. 203-304-7219

ADDITIONAL RECOMMENDED STEPS

We recommend you remain vigilant and consider taking the following steps to avoid identity theft, obtain additional information, and protect your personal information:

- Order Your Free Credit Report at www.annualcreditreport.com, call toll-free at 877-322-8228, or complete the Annual Credit Report Request Form on the U.S. Federal Trade Commission's website at www.ftc.gov. When you receive your credit report, review the entire report carefully. Look for any inaccuracies and/or accounts you don't recognize and notify the credit bureaus as soon as possible in the event there are any. You have rights under the federal Fair Credit Reporting Act ("FCRA"). These include, among others, the right to know what is in your file; to dispute incomplete or inaccurate information; and to have consumer reporting agencies correct or delete inaccurate, incomplete, or unverifiable information.
- Place a fraud alert on your credit file. In addition to the security freeze detailed above, a fraud alert helps protect you against an identity thief opening new credit in your name. With this alert, when a merchant checks your credit history when you apply for credit, the merchant will receive a notice that you may be a victim of identity theft and to take steps to verify your identity. You can place a fraud alert by contacting the credit bureaus. The credit bureaus may require that you provide proper identification prior to honoring your request.

Equifax Consumer Fraud Division P.O. Box 740256 Atlanta, GA 30374 800-525-6285 securitymonitoring@equifax.com Experian
Experian Security Assistance
P.O. Box 72
Allen, TX 75013
888-397-3742
businessrecordsvictimassistance@experian.com

TransUnion Consumer Relations & Fraud Victim Assistance P.O. Box 2000 Chester, PA 19016 800-372-8391 databreach@Transunion.com

- Remove your name from mailing lists of pre-approved offers of credit for approximately six months.
- If you are not already doing so, please pay close attention to all bills and credit card charges you receive for items you did not contract for or purchase. Review all of your bank account statements frequently for checks, purchases or deductions not made by you. Note that even if you do not find suspicious activity initially, you should continue to check this information periodically since identity thieves sometimes hold on to stolen personal information before using it.

The Federal Trade Commission ("FTC") offers consumer assistance and educational materials relating to identity theft, privacy issues, and how to avoid identity theft. You may also obtain information about fraud alerts and security freezes from the consumer reporting agencies, your state Attorney General, and the FTC. If you detect any incident of identity theft or fraud, promptly report the incident to your local law enforcement authorities, your state Attorney General, and/or the Federal Trade Commission. You can learn more about how to protect yourself from becoming an identity theft victim (including how to place a fraud alert or security freeze) by contacting the FTC at 1-877-IDTHEFT (1-877-438-4338), or www.ftc.gov/idtheft. The mailing address for the FTC is: Federal Trade Commission, Consumer Response Center, 600 Pennsylvania Avenue, NW Washington, DC 20580.