



Tuberous Sclerosis Alliance
 8737 Colesville Road
 Suite 400
 Silver Spring, MD 20910

October 1, 2020

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SAMPLE A SAMPLE - L01 ADULT
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 ANYTOWN, US 12345-6789



Dear Sample A Sample:

The Tuberous Sclerosis Alliance (TS Alliance) writes to tell you about an issue that has been brought to our attention. Because maintaining your trust and protecting the security of your information are our highest priorities, we want to provide you with details surrounding this event. On Thursday, July 16, 2020, one of our vendors, Blackbaud, Inc. (“Blackbaud”) informed us that it suffered a ransomware attack that resulted in potential unauthorized access to certain information maintained by its systems. Blackbaud, an industry-leading cloud computing provider, is where we house our constituent and donor database. Unfortunately, Blackbaud’s incident impacted a significant number of organizations, including the TS Alliance. This notice provides information about the Blackbaud incident, our response, and resources available to you to help protect your information from possible misuse, should you feel it necessary to do so.

Blackbaud reported that, in May 2020, it experienced a ransomware incident that resulted in encryption of certain Blackbaud systems. Blackbaud reported the incident to law enforcement and worked with forensic investigators to determine the nature and scope of the incident. Following its investigation, Blackbaud notified its customers that an unknown actor may have accessed or acquired certain Blackbaud customer data. Blackbaud reported that the data was exfiltrated by the threat actor at some point before Blackbaud locked the threat actor out of the environment on May 20, 2020.

Once we learned about this event, we immediately commenced an investigation to determine what, *if any*, sensitive TS Alliance data was potentially affected. Blackbaud advised they worked with forensic experts and law enforcement to investigate the incident. In addition, **Blackbaud informed us that the hackers did not access credit card information and that bank account information, usernames, passwords and Social Security numbers that were stored in fields encrypted by Blackbaud were not accessible to the hackers because of the encryption.**

On or about August 5, 2020, TS Alliance received further information from Blackbaud that allowed it to determine the information potentially affected may have contained personal information.

Our investigation determined that the involved Blackbaud systems contained your name, address and [Extra1]. Please note that, to date, we have not received confirmation from Blackbaud that your specific information was accessed or acquired by the unknown actor.

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Please know the TS Alliance and our Board of Directors take this incident and the security of the personal information entrusted to us very seriously, and we are diligently working to determine the full nature and scope of what happened. As part of our ongoing commitment to the security of information in our care, we are working to review our existing policies and procedures regarding our third-party vendors, and are working with Blackbaud to evaluate additional measures and safeguards to protect against this type of incident in the future. We will also be notifying state regulators as required. While we work to better understand this event, we are reaching out to you as a valued member of the TSC community in the interest of transparency. We sincerely regret any concern this incident may cause you.

We encourage you to review the enclosed *Steps You Can Take to Help Protect Your Information*. There you will find general information on what you can do to help protect your personal information.

We understand that you may have questions about the Blackbaud incident that are not addressed in this letter. If you have additional questions, please contact Lisa Moss, Senior Director of Donor Relations at (301) 562-9890 x 222 between the hours of 9 a.m. to 5 p.m. EST, Monday to Friday. You may also write to the Tuberous Sclerosis Alliance at 8737 Colesville Road, Suite 400, Silver Spring, MD 20910.

We sincerely regret any inconvenience or concern this incident has caused.

Sincerely,

A handwritten signature in cursive script, appearing to read "Kari Luther Rosbeck".

Kari Luther Rosbeck
President and CEO

STEPS YOU CAN TAKE TO HELP PROTECT YOUR INFORMATION

Monitor Accounts

In general, we encourage you to remain vigilant against incidents of identity theft and fraud, to review your account statements, and to monitor your credit reports for suspicious activity. Under U.S. law you are entitled to one free credit report annually from each of the three major credit reporting bureaus. To order your free credit report, visit www.annualcreditreport.com or call, toll-free, 1-877-322-8228. You may also contact the three major credit bureaus directly to request a free copy of your credit report.

You have the right to place a “security freeze” on your credit report, which will prohibit a consumer reporting agency from releasing information in your credit report without your express authorization. The security freeze is designed to prevent credit, loans, and services from being approved in your name without your consent. However, you should be aware that using a security freeze to take control over who gets access to the personal and financial information in your credit report may delay, interfere with, or prohibit the timely approval of any subsequent request or application you make regarding a new loan, credit, mortgage, or any other account involving the extension of credit. Pursuant to federal law, you cannot be charged to place or lift a security freeze on your credit report. Should you wish to place a security freeze, please contact the major consumer reporting agencies listed below:

Experian

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

TransUnion

P.O. Box 160
Woodlyn, PA 19094
1-888-909-8872
www.transunion.com/credit-freeze

Equifax

P.O. Box 105788
Atlanta, GA 30348-5788
1-800-685-1111
www.equifax.com/personal/credit-report-services

In order to request a security freeze, you will need to provide the following information:

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, provide the addresses where you have lived over the prior five years;
5. Proof of current address, such as a current utility bill or telephone bill;
6. A legible photocopy of a government-issued identification card (state driver’s license or ID card, military identification, etc.);
7. 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.

As an alternative to a security freeze, you have the right to place an initial or extended “fraud alert” on your file at no cost. An initial fraud alert is a 1-year alert that is placed on a consumer’s credit file. Upon seeing a fraud alert display on a consumer’s credit file, a business is required to take steps to verify the consumer’s identity before extending new credit. If you are a victim of identity theft, you are entitled to an extended fraud alert, which is a fraud alert lasting seven years. Should you wish to place a fraud alert, please contact any one of the agencies listed below:

Experian

P.O. Box 9554
Allen, TX 75013
1-888-397-3742
www.experian.com/fraud/center.html

TransUnion

P.O. Box 2000
Chester, PA 19016
1-800-680-7289
www.transunion.com/fraud-victim-resource/place-fraud-alert

Equifax

P.O. Box 105069
Atlanta, GA 30348
1-888-766-0008
www.equifax.com/personal/credit-report-services



Additional Information

You can further educate yourself regarding identity theft, fraud alerts, security freezes, and the steps you can take to protect yourself by contacting the consumer reporting agencies, the Federal Trade Commission, or your state Attorney General.

The Federal Trade Commission can be reached at: 600 Pennsylvania Avenue NW, Washington, DC 20580; www.identitytheft.gov; 1-877-ID-THEFT (1-877-438-4338); and TTY: 1-866-653-4261. The Federal Trade Commission also encourages those who discover that their information has been misused to file a complaint with them. You can obtain further information on how to file such a complaint by way of the contact information listed above. You have the right to file a police report if you ever experience identity theft or fraud. Please note that in order to file a report with law enforcement for identity theft, you will likely need to provide some proof that you have been a victim. Instances of known or suspected identity theft should also be reported to law enforcement and your state Attorney General.

Maryland Residents: Office of the Attorney General of Maryland, Consumer Protection Division 200 St. Paul Place Baltimore, MD 21202, www.oag.state.md.us/Consumer, Telephone: 1-888-743-0023.

Oregon Residents: Oregon Department of Justice, 1162 Court Street NE, Salem, OR 97301-4096, www.doj.state.or.us/, Telephone: 877-877-9392.