**CMTA Data Breach FAQs**

**Who was impacted?**

* How many donors were impacted by this data breach?
  + The breach impacted all donors in our database at the time of the download in 2017—approximately 43,000 individuals, entities, and groups.
* How do I know if my information was downloaded?
  + If you were a donor to CMTA r prior to December 2017, then your information was downloaded, and it is expected that your contact information was included in the breach. We want to assure you the forensics report confirmed that no credit card, Social Security numbers or bank account information were compromised and now, all information has been returned and destroyed with the assistance of a third-party forensic firm.
* What information did CMT Research Foundation retain?
  + In some instances, CMT Research Foundation was able to show that it had independently collected contact information for certain individuals from direct mailers, social media outreach or other means (independent of use of the downloaded CMTA list). In those limited instances, CMT Research Foundation retained the contact information of individuals that are also on CMTA’s donor list. If you continue to receive information from the CMT Research Foundation and you do not wish to receive those materials, you will need to contact that organization directly to request removal from their contact lists.
* Why was the information taken?
  + The investigation revealed that only portions of the donor list were used, and the use centered around another CMT organization building its own outreach list, social media presence and for soliciting donations from the donors. The Court required return of the donor list and information derived from the list and after an extensive forensic investigation and assurances from the former employee, the other CMT organization and their counsel, CMTA is confident that the list has been returned and removed from the third parties’ possession.

**Identity Protection**

* What steps should I take if I believe my information was downloaded?
  + We want to assure you the forensics investigation confirmed that no credit card, Social Security numbers or bank account information were compromised. As a matter of practice, we did not store this type of information in our donor system at the time of the incident. Today, any sensitive financial information is encrypted in the system for an additional layer of safety and security.
  + For these reasons, we are not currently recommending any individual action by donors. However, if you choose to review the best practices for monitoring your information and identity online, please review the [FTC’s guidelines](https://www.consumer.ftc.gov/topics/identity-theft).
* What is CMTA doing to help protect my identity?
  + We immediately added additional security and controls to our donor system, limiting access and download capabilities to key CMTA personnel.
  + We have completed the return of the information downloaded by Susan Ruediger.
  + Our forensics partner is identifying additional safety and security measures for future potential implementation.
  + We are continuing to screen all prospective staff members and consultants through a variety of measures, including background checks and a shared belief in our core values.
* Are you offering credit monitoring to the donors whose information was compromised?
  + Because our forensics report confirmed that no credit card, Social Security numbers or bank account information were compromised, CMTA and its legal and accounting advisors are not recommending additional credit monitoring at this time. Additionally, the investigation indicates the access was not for the purpose of identity theft or fraud, but in order to solicit donations from the donors by a third party. If you wish, you may choose to review the best practices for monitoring your information and identity online via the [FTC’s guidelines](https://www.consumer.ftc.gov/topics/identity-theft).

**What action has the CMTA taken?**

* What is the CMTA doing to prevent something like this from happening again?
  + We immediately added additional security and controls to our donor system, further limiting access and download capabilities to key CMTA personnel.
  + Our forensics partner is identifying additional safety and security measures for future potential implementation.
  + We are continuing to screen all prospective staff members and consultants through a variety of measures, including background checks and a shared belief in our core values.
* Why did the CMTA take legal action against Susan Ruediger and the CMT Research Foundation?
* We had a legal and ethical obligation to protect our donors’ data and their privacy and to understand if and how that information had been used or exposed.

**Future CMTA Impact**

* Why should I trust CMTA with my money and data in the future?
  + We are proud to be the only 4-star rated CMT-focused organization by Charity Navigator, the nation’s largest and most-utilized evaluator of charities.
  + We remain steadfastly committed to our financial obligations to the CMT community and our cause—a minimum of [90 cents of every dollar](https://www.cmtausa.org/about/annual-reports-finances-and-policies/cmta-financial-information/) we spend will continue to go toward improving the quality of life, helping develop treatments and searching for a cure for those impacted by CMT.
  + Upon learning about the breach, we immediately took the following steps:
    1. Added additional security and controls to our donor system, limiting access and download capabilities to key CMTA personnel,
    2. Began pursuing the return of the information taken by the former employee and the organization she founded,
    3. And engaged a forensics partner to identify additional safety and security measures for future potential implementation.
  + Over the last 13 years, we have made tremendous progress through STAR (Strategy to Accelerate Research), which has led to the identification of the genes that cause CMT and the utilization of rapid drug discovery and preclinical technologies to identify therapies that modify the CMT disease process.
  + In 2021, we will also be:
    1. Expanding our Strategy to Accelerate Research (STAR) by 26%, investing $600K more than last year on promising projects,
    2. Expanding our partnerships with biotech and pharma companies, including work on exciting new approaches to treat CMT with gene therapy through collaborations with 4 gene therapy companies,
    3. Hosting Camp Footprint and increasing the number of campers that will be participating in this week-long summer camp program, which is the only camp just for kids with CMT,
    4. Providing education and support through our 70+ branches and through virtual education programs like our monthly Zoom series, and more.