

TEAM TITIN PRIVACY POLICY

Adopted and last updated: January 17, 2026

This notice explains how Team Titin, Inc. (“Team Titin”, “we”, “us”) collects and uses personal data on our website (www.TitinMyopathy.com) and related digital properties. It is written to meet the transparency requirements of the UK GDPR / EU GDPR. This document updates and supersedes prior versions of our privacy policy. Team Titin, Inc. is a U.S. 501(c)(3) nonprofit supporting people affected by titin (TTN)-related muscle and heart conditions. For this website, Team Titin acts as the data controller.

PRIVACY POLICY TERMS

Team Titin, Inc. (“us”, “we”, or “our”) operates the titinmyopathy.com website (hereinafter referred to as the “Service”). This document informs you of our policies regarding the collection, use, and disclosure of personal data when you use our Service and the choices you have associated with that data.

We use your data to provide and improve the Service and support our mission. By using the Service, you agree to the collection and use of information in accordance with this policy.

WE RESPECT YOUR CONFIDENTIALITY

Your personal data will be held in strict confidence. We use your information only for its intended purpose to fulfill our mission. We do not sell or trade your information to other organizations or individuals. We share limited data with service providers (processors) that help us operate our website and communications, such as:

- Website hosting and security providers
- Email/newsletter service providers
- Web analytics providers (for example, if enabled)
- Event/registration platforms (when you choose to register)

These providers are bound by contract to use personal data only to provide services to us and to keep it secure.

WE PROTECT YOUR INFORMATION

If you choose to send us an email, we may retain the contents of your email message, your contact information, our reply and your email address as part of our ongoing customer service efforts. We reserve the right to contact you after you have contacted us and may send future email and/or surveys to you about Team Titin, Inc. You may notify us via email if you wish to discontinue electronic communication.

WE KEEP ACCURATE RECORDS

We keep your personal data as accurate, complete, and up to date as is required to fulfill the purpose(s) for which you provided it to us. Upon written request (including email) we will remove your personal data from our databases, except where legislation or regulation requires our retention of it (for example, charitable giving history tied to income tax receipts). You may request a copy of your information, request to delete your information, or request to remove yourself from our databases by communicating with us via the contact information listed at the very end of this policy.

INFORMATION COLLECTION AND USE - Scope and exclusions

We collect several different types of information for various purposes to provide and improve our Service to you.

This policy covers personal data collected via our website, contact forms, event or newsletter sign-ups, and general inquiries. This policy also covers certain survey or intake information that you may choose to provide to Team Titin in connection with our advocacy partnership with [Citizen Health](#). Team Titin partners with Citizen Health to offer our community an optional tool to help individuals organize their health information and, if they choose, contribute to research efforts related to titin-related conditions.

If you choose to participate, Team Titin may collect information you submit through Team Titin forms or surveys in order to support community engagement, evaluate our programs, advance research and facilitate your requested connection to the Citizen Health platform. Team Titin may use this information only in ways consistent with the consent you execute in connection with the Citizen Health Dashboard (“Dashboard Consent”). If you want to opt-out of receiving any surveys, please send an e-mail to Sarah Foye at Sarah@teamtitin.org.

Once your information is on the Citizen Health platform, Citizen Health’s collection, use, and disclosure of that information is governed by Citizen Health’s own terms and [privacy policy](#).

This policy does not cover the Congenital Muscle Disease International Registry (CMDIR). CMDIR is operated separately and has its own privacy policy at www.cmdir.org.

PERSONAL DATA

While using our Service, we may ask you to provide us with certain personally identifiable information that can be used to contact or identify you (“Personal Data”). Personally identifiable information may include, but is not limited to:

- Email address
- First name and last name
- Phone number
- Address, city, state, ZIP/postal code, province
- Cookies and Usage Data

We do not ask for health information via our website forms. Please do not include detailed medical information in open text fields.

CHILDREN’S PRIVACY

Our website is intended for a general audience and is not directed to children under 13. We do not knowingly collect personal data from children via the website.

USAGE DATA

We may also collect information on how the Service is accessed and used (“Usage Data”). This Usage Data may include information such as your computer’s Internet Protocol address (e.g. IP address), browser type, browser version, the pages of our Service that you visit, the time and date of your visit, the time spent on those pages, unique device identifiers and other diagnostic data.

TRACKING AND COOKIES DATA

We use cookies and similar tracking technologies to track the activity on our Service and we hold certain information.

Cookies are files with a small amount of data which may include an anonymous unique identifier. Cookies are sent to your browser from a website and stored on your device. Other tracking technologies are also used such as beacons, tags and scripts to collect and track information and to improve and analyze our Service.

We use a cookie consent tool to obtain user permission before setting non-essential cookies. You may withdraw or update your cookie preferences at any time by clicking your preference on the cookie banner on our website. You can instruct your browser to refuse all cookies or to indicate when a cookie is being sent. However, if you do not accept cookies, you may not be able to use some portions of our Service.

Examples of Cookies we use:

- Session Cookies. We use Session Cookies to operate our Service.
- Preference Cookies. We use Preference Cookies to remember your preferences and various settings.
- Security Cookies. We use Security Cookies for security purposes.

USE OF DATA

Team Titin, Inc. uses the collected data for various purposes:

- To provide and maintain the Service
- To notify you about changes to our Service
- To allow you to participate in interactive features of our Service when you choose to do so
- To provide customer care and support
- To provide analysis or valuable information so that we can improve the service
- To monitor the usage of the Service
- To detect, prevent and address technical issues
- To support our mission
- To facilitate participation in our advocacy partnership with [Citizen Health](#) if you choose to enroll, including sharing information as permitted by your Citizen Health Dashboard Consent.

Why we use your data and our lawful bases

We use personal data for the purposes below and rely on the corresponding legal bases:

Purpose	Legal basis (UK/EU GDPR)
Respond to inquiries and manage relationships (emails, contact forms).	Legitimate interests (to operate our nonprofit and respond to requests); or Contract if you ask us to take steps before entering into an agreement (e.g., event registration).
Send newsletters and updates you request.	Consent (you can withdraw at any time).
Operate and secure the website; detect, prevent and address technical issues.	Legitimate interests (site operation, security).
Analytics to understand site use and improve content (non-essential cookies).	Consent (opt-in before setting non-essential cookies).
Comply with legal obligations (e.g., charity records, tax).	Legal obligation.

HOW LONG WE KEEP YOUR DATA (retention)

We keep personal data only as long as needed for the purpose collected:

- General inquiries: indefinitely unless requested to be removed
- Newsletter subscriptions: until you unsubscribe; we honor opt-outs
- Donation/finance records: typically 7 years (tax/charity laws)

- Web server logs and security records: up to 12 months

We may retain data longer if required by law, to resolve disputes, or enforce agreements.

TRANSFER OF DATA

Your information, including Personal Data, may be transferred to and maintained on, computers located outside of your state, province, country or other governmental jurisdiction where the data protection laws may differ from those in your jurisdiction.

If you are located outside the United States and choose to provide information to us, please note that we transfer the data, including Personal Data, to the United States and process it there.

Your consent to this Privacy Policy followed by your submission of such information represents your agreement to the transfer of that information.

Team Titin, Inc. will take all steps reasonably necessary to ensure that your data is treated securely and in accordance with this Privacy Policy and no transfer of your Personal Data will take place to an organization or a country unless there are adequate controls in place, including the security of your data and other personal data.

DISCLOSURE OF DATA

The Team Titin, Inc. shall provide you with the recipients or categories of recipients of your personal data, if any.

LEGAL REQUIREMENTS

Team Titin, Inc. may disclose your Personal Data in the good faith belief that such action is necessary to:

- To comply with a legal obligation
- To protect and defend the rights or property of Team Titin, Inc.
- To prevent or investigate possible wrongdoing in connection with the Service
- To protect the personal safety of users of the Service or the public
- To protect against legal liability

SECURITY OF DATA

The security of your data is important to us but remember that no method of transmission over the Internet or method of electronic storage is 100% secure. While we strive to use commercially acceptable means to protect your Personal Data, we cannot guarantee its absolute security.

DATA BREACH Once aware of a data breach, we will follow relevant laws concerning reporting of the breach. Team Titin, Inc. will work without undue delay after becoming aware of a data breach to gather all related information, conduct a thorough investigation, inform impacted individuals of the breach, identify what personal data has been impacted and how; and draft a comprehensive containment plan, reporting data breaches to the relevant regulator, such as the New Jersey Cybersecurity and Communications Integration Cell (NJCCIC). If we are unable to provide prompt notification we will provide reasonable justification for the delay; which may be caused by potentially adding additional disruption to regular business operations and exasperating administrative hassle. Because we process EU/UK personal data only occasionally, most EU/UK breach reporting obligations do not apply to us; however, we follow U.S. state breach laws and general best practices.

SERVICE PROVIDERS AND ANALYTICS

We may employ third party companies and individuals to facilitate our Service ("Service Providers"), to provide the Service on our behalf, to perform Service-related services or to assist us in analyzing how our Service is used. These third parties have access to your Personal Data only to perform these tasks on our behalf and are obligated not to disclose or use it for any other purpose. We may use third-party Service Providers to monitor and analyze the use of our Service. These may include the following, or similar, service providers:

Processor	Purpose	Location	Privacy Policy
ConstantContact	Newsletter delivery	USA	Constant Contact privacy practices link https://knowledgebase.constantcontact.com/email-digital-marketing/articles/KnowledgeBase/5536-Constant-Contact-privacy-practices?lang=en_US
WordPress	Site hosting/plugins	USA	Privacy policy link: https://wordpress.org/about/privacy/
Google Analytics	Web analytics	USA	Privacy Policy: https://policies.google.com/privacy?hl=en&gl=ZZ
GoDaddy	Hosting	USA	GoDaddy - Global Privacy Notice link: https://www.godaddy.com/legal/agreements/privacy-policy

LINKS TO OTHER SITES

Our Service may contain links to other sites that are not operated by us. If you click a third-party link, you will be directed to that third party's site. We strongly advise you to review the Privacy Policy of every site you visit. We have no control over and assume no responsibility for the content, privacy policies or practices of any third-party sites or services.

CHANGES TO THIS PRIVACY POLICY

We may update our Privacy Policy from time to time. We will notify you of any changes by posting the new Privacy Policy on this page. You are advised to review this Privacy Policy periodically for any changes. Changes to this Privacy Policy are effective when they are posted on this page.

UNSUBSCRIBE

If you no longer wish to receive emails, please click the "unsubscribe" link at the bottom of our emails or contact us using the information at the end of this document.

YOUR DATA PROTECTION RIGHTS (UK/EU data subjects)

You have rights over your personal data, subject to conditions and exemptions in law: access; rectification; erasure; restriction; portability; objection (including to processing based on legitimate interests); and the right to withdraw consent at any time where processing is based on consent. You also have the right to lodge a complaint with the UK Information Commissioner's Office (ICO) or your local EU data protection authority. To exercise your rights, contact us at sarah@teamtitin.org. We may need to verify your identity and will respond within one month, or explain if more time is needed.

Team Titin, Inc. is a U.S.-based nonprofit organization. Under the EU GDPR and UK GDPR, organizations located outside the EU/UK must appoint an Article 27 Representative unless their processing of personal data is occasional, not large-scale, does not involve special categories of data, and does not include monitoring behavior of individuals in the EU/UK. We have assessed our activities and believe that Team Titin does not require an EU or UK Representative at this time, because: We do not collect health or genetic information through our website. We only collect first name, last name, and email address for newsletter sign-ups and basic inquiries. Any interactions with individuals in the EU/UK are occasional and not part of targeted outreach. We do not conduct

large-scale tracking or profiling of EU/UK individuals. Google Analytics is used only for aggregated website statistics and ad-grant reporting, not for individualized tracking. If our activities change in the future such that an Article 27 Representative becomes required, we will update this Privacy Policy accordingly and publish the contact details of the appointed representative. EU/UK individuals may continue to exercise their data protection rights by contacting us as listed below.

CONTACT US

If you have any questions about this Privacy Policy, requests or complaints please contact Sarah Foye, our Data Protection Officer:

- By email: Sarah@TeamTitin.org
- By phone number: (973) 797-9305
- By mail: PO Box 794, Pine Brook, NJ 07058

DEFINITIONS

- **Service**
Service is the titinmyopathy.com website operated by Team Titin, Inc.
- **Personal Data**
Personal Data means data about an individual who can be identified from that data (or from other information either in our possession or likely to come into our possession).
- **Usage Data**
Usage Data is data collected automatically and either generated by the use of the Service or from the Service infrastructure itself (for example, the duration of a page visit).
- **Cookies**
Cookies are small files stored on your device (computer or mobile device).