

Team Titin PRIVACY POLICY

Adopted: January 8, 2023

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 information 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 PROTECT YOUR INFORMATION

If you choose to send us email, we may retain the contents of your email message, 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 information 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 information 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

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

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

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.

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

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 information.

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.

SERVICE PROVIDERS

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.

ANALYTICS

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:

- Google Analytics a web analytics service. You can visit their Privacy Policy page here: [https:// policies.google.com/privacy?hl=en&gl=ZZ](https://policies.google.com/privacy?hl=en&gl=ZZ)

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.

OUR REGISTRY

Our registry, the Congenital Muscle Disease International Registry (CMDIR) has its own privacy policy found on the website www.cmdir.org under the "Privacy Policy" tab.

CONTACT US

If you have any questions about this Privacy Policy, please contact Sarah Foye, our Data Privacy 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).