

# Privacy Policy

Effective Date: June 26, 2023

This Privacy Policy ("Privacy Policy") describes practices in connection with information that the Macitentan REMS (Risk Evaluation and Mitigation Strategy) collects through the website (hereinafter the "Service") from which you are accessing this Privacy Policy. This REMS is a risk management strategy required by the U.S. Food and Drug Administration ("FDA") to be governed by The Macitentan REMS ("we", or "us", or "our"), a consortium of manufacturers, its agents, affiliates, and authorized representatives. We encourage you to read the full Privacy Policy and, if applicable to you, the Supplemental Notice, before using this Service or providing any Personal Information. By providing Personal Information to the Macitentan REMS by using the Service you acknowledge that you have read and understand this Privacy Policy and that you consent to the Macitentan REMS using and sharing your Personal Information consistent with this Privacy Policy and the purposes and requirements of the Macitentan REMS and the Service.

## DEFINITIONS

- "Personal Information" means information that identifies, relates to, describes, is reasonably capable of being associated with, or could reasonably be linked, directly or indirectly, with a particular consumer or household. Personal Information includes "personal data" as that term is defined in applicable US State Privacy Laws. Personal Information also includes "Sensitive Personal Information," as defined below, except where otherwise noted.
- "Sensitive Personal Information" means Personal Information that reveals a consumer's account log-in information in combination with any required security or access code, password, or credentials allowing access to an account; racial or ethnic origin; contents of email or text messages; and genetic data. Sensitive Personal Information also includes processing of biometric information for the purpose of uniquely identifying a consumer and Personal Information collected and analyzed concerning a consumer's health, sex life, or sexual orientation. Sensitive Personal Information also includes "sensitive data" as that term is defined in applicable US State Privacy Laws.

To the extent other terms used in this Privacy Policy and Supplemental Notice are defined terms under applicable US State Privacy Laws, they shall have the meanings afforded to them in those statutes, whether or not capitalized herein. As there are some variations between such definitions in each of the state statutes, the definitions applicable to you are those provided in the statute for the state in which you are a consumer. For example, if you are a Virginia consumer, terms used in this Privacy Policy and Supplemental Privacy Notice that are defined terms in the VCDPA shall have the meanings afforded to them in the VCDPA as this Privacy Policy and Supplemental Privacy Notice applies to you.

## PERSONAL INFORMATION COLLECTED

When you use the Service, it may collect Personal Information about you.

If you submit any Personal Information relating to another individual, you represent that you have the authority to do so and to permit the Service and the Macitentan REMS to use the information in accordance with this Privacy Policy.

The Macitentan REMS, and our Vendors or Third Parties, may collect, process, and disclose the following categories of Personal Information:

- (1) Identifiers, such as name, alias, online identifiers, account name, physical characteristics or description;
- (2) Contact and financial information, including phone number, address, email address, financial information, medical information, health insurance information;

- (3) Characteristics of protected classifications under state or federal law, such as age, gender, race, physical or mental health conditions, and marital status;
- (4) Internet or other electronic network activity information, such as browsing history, search history and interactions with our websites or advertisements;
- (5) Audio, electronic, visual and similar information, such as call and video recordings;
- (6) Professional or employment-related information, such as specialty, education history, professional qualifications, work history and prior employer;
- (7) Inferences drawn from any of the Personal Information listed above to create a profile or summary about, for example, an individual's preferences and characteristics; and
- (8) Sensitive Personal Information, including:
  - a. Personal Information that reveals:
    - i. Account log-in in combination with any required security or access code, password, or credentials for allowing access to an account;
    - ii. Racial or ethnic origin, religious or philosophical beliefs, or union membership;
  - b. Biometric data processed for the purpose of uniquely identifying a consumer;
  - c. Personal Information collected and analyzed concerning a consumer's health; and
  - d. Personal Information collected and analyzed concerning a consumer's sex life or sexual orientation.

We may also combine the information you submit with information we have already collected from you, whether on or offline, which may also include your information from external sources.

If you are using the Service as a patient, your prescriber will collect your electronic signature during enrollment. Note that your electronic signature has the same effect as your handwritten signature.

The Macitentan REMS is committed to protecting the privacy and accuracy of your Personal Information to the extent possible and your Personal Information will not be sold for any reason.

## SENSITIVE INFORMATION

Unless the Service specifically requests or invites it, the Macitentan REMS asks that you not send, and you not disclose, any sensitive Personal Information (e.g., Social Security numbers, information related to racial or ethnic origin, political opinions, religion or philosophical beliefs, health or medical condition, sex life or sexual orientation, criminal background, or trade union membership, or biometric or genetic data) on or through the Service or otherwise directly to the Macitentan REMS.

## AUTOMATIC INFORMATION COLLECTION AND USE

The Service and its service providers may automatically collect and use information in the following ways as you navigate around the Service:

**Through your browser:** Certain information is collected by most browsers, such as your Media Access Control (MAC) address, computer type (Windows or Mac), screen resolution, operating system name and version, and Internet browser type and version. The Service may collect similar information, such as your device type and identifier, if you access the Service through a mobile device. The Service uses this information to ensure that the Service functions properly.

**Using cookies:** Cookies are pieces of information stored directly on the computer you are using. Cookies allow the Service to collect information such as browser type, time spent on the Service, pages visited, and language preferences. The Service and its service providers use the information for security purposes, to facilitate navigation, display information more effectively, and to personalize your experience while using the Service. The Service also uses cookies to recognize your computer or device, which makes your use of the Service easier. In addition, the Service uses cookies to gather statistical information about Service usage in order to continually improve its design and functionality, understand how individuals use it, and to assist with resolving questions regarding it.

You can refuse to accept these cookies by following your browser's instructions; however, if you do not accept them, you may experience some inconvenience in your use of the Service. To learn more about cookies, please visit <http://www.allaboutcookies.org>.

**IP address:** Your IP address is a number that is automatically assigned to your computer by your Internet Service Provider. An IP address is identified and logged automatically in the server log files whenever a user visits the Service, along with the time of the visit and the pages visited. Collecting IP addresses is standard practice and is done automatically by many online services. The Service use IP addresses for purposes such as calculating Service usage levels, diagnosing server problems, and administering the Service. The Service may also derive your approximate location from your IP address.

## SOURCES FROM WHICH THE MACITENTAN REMS COLLECTS PERSONAL INFORMATION

The Macitentan REMS collects Personal Information directly from you as well as from our affiliates, business partners, joint marketing partners, public databases, providers of demographic data, publications, professional organizations, social media platforms, caregivers, third party information providers, affiliates with whom you have a business relationship, service providers with which the Macitentan REMS has a contractual relationship and to which you have provided your Personal Information, cookies and other tracking technologies, and Vendors and Third Parties when they share the information with the Macitentan REMS.

## HOW WE USE YOUR PERSONAL INFORMATION

The Macitentan REMS uses and discloses information you provide to the Service as described to you at the point of collection. Where required by applicable law, we will obtain your consent to allow the Service use of your Personal Information at the point of information collection.

The Macitentan REMS, and our Vendors, collect and process the Personal Information (excluding Sensitive Personal Information) to:

- Operate, manage, and maintain our business;
- Respond to your inquiries and to fulfill your requests;
- Send you important information regarding our relationship with you or regarding this website, changes to our terms, conditions, and policies and/or other administrative information;
- Conduct audits, to verify that our internal processes function as intended and are compliant with legal, regulatory, or contractual requirements;
- Prevent fraud or crime, and for risk and technical security monitoring purposes;
- Facilitate the development of new products and services;
- Enhance, improve or modify our website or products and services;
- Perform research, analytics and, data analysis;
- Personalize, advertise, and market our products and services;
- Comply with law, legal process, and internal policies;
- Maintain records;
- Exercise and defend legal claims; and
- Otherwise accomplish our business purposes and objectives.

The Macitentan REMS, and our Vendors, collect and process the Sensitive Personal Information described in this Privacy Policy for:

- Performing the services or providing the goods reasonably expected by an average consumer who requests those goods or services;
- Ensuring security and integrity to the extent the use of the consumer's Personal Information is reasonably necessary and proportionate for these purposes;
- Performing services on our behalf, including maintaining or servicing accounts, providing customer service, processing or fulfilling orders and transactions, verifying customer information, processing payments, providing financing, providing analytic services, providing storage, or providing similar services on our behalf;
- Undertaking activities to verify or maintain the quality or safety of a service or device that is owned, manufactured, manufactured for, or controlled by the Macitentan REMS, and to improve, upgrade, or enhance the service or device that is owned, manufactured, manufactured for, or controlled by the Macitentan REMS;
- Personalizing, advertising, and marketing our products and services;
- Conducting research, analytics, and data analysis;
- Performing accounting, audit, and other internal functions, such as internal investigations;
- Complying with law, legal process, and internal policies;
- Maintaining records;
- Exercising and defending legal claims; and
- Otherwise accomplishing our business purposes and objectives.

## HOW AND WHY WE DISCLOSE YOUR PERSONAL INFORMATION

- **Affiliates & Vendors.** The Macitentan REMS may disclose your Personal Information to our affiliates and vendors for the purposes described in the section “Purposes for Processing Personal Information.” Our vendors provide the Macitentan REMS with services for our websites, as well as other products and services, such as web hosting and moderating, mobile application hosting, data analysis, payment processing, order fulfillment, customer service, infrastructure provision, technology services, email and direct mail delivery services, auditing, legal services, and other similar services. The Macitentan REMS grants our vendors access to Personal Information only to the extent needed for them to perform their functions and require them to protect the confidentiality and security of such information.
- **Third Parties.** The Macitentan REMS may disclose your Personal Information to the following categories of third parties:
  - **At Your Direction.** The Macitentan REMS may disclose your Personal Information to any third party with your consent or at your direction.
  - **Business Transfers or Assignments.** The Macitentan REMS may disclose your Personal Information to other entities as reasonably necessary to facilitate a reorganization, merger, sale, joint venture or collaboration, assignment, transfer, or other disposition of all or any portion of our business, assets, or stock (including in connection with any bankruptcy or similar proceedings).
  - **Third Party Co-Branding and Co-Marketing Partners.** The Macitentan REMS may share your Personal Information with our third party partners with whom we offer a co-branded or co-marketed promotion.

- **Third Party Advertising Partners.** To improve the effectiveness of our communication with you and our marketing campaigns, The Macitentan REMS may share our data with our third party advertising partners, including social media, medical journals and publishers.
- **Legal and Regulatory.** The Macitentan REMS may disclose your Personal Information to government authorities, including regulatory agencies and courts, as reasonably necessary for our business operational purposes, to assert and defend legal claims, and otherwise as permitted or required by law.

## SECURITY

The Macitentan REMS seeks to use reasonable organizational, technical, and administrative measures designed to protect Personal Information under the Service's control. However, no data transmission over the Internet or data storage system can be guaranteed to be 100% secure. If you have reason to believe that your interaction with the Service is no longer secure (for example, if you feel that the security of any account you have with the Service has been compromised), please immediately notify the Macitentan REMS in accordance with the "Contacting Us" section below.

## RETENTION PERIOD

The Macitentan REMS will retain your Personal Information for as long as needed or permitted in light of the purpose(s) for which it was obtained. The criteria used to determine retention periods include: (i) the length of time we have an ongoing relationship with you and provide the Service to you; (ii) whether there is a legal obligation to which we are subject; and (iii) whether retention is advisable in light of the Service's legal position (such as, in regard to applicable statutes of limitations, litigation or regulatory investigations).

## THIRD PARTY SITES AND SERVICES

This Service may contain links to sites of third parties. This Privacy Policy does not address, and the Macitentan REMS is not responsible for, the privacy, information, or practices of any third parties, including any third party operating any site or online service (including, without limitation, any application) that is available through this Service or to which this Service contains a link. The availability of, or inclusion of a link to, any such site or property on the Service does not imply endorsement of it by the Macitentan REMS or by the Service's affiliates.

## USE BY MINORS - CHILDREN'S DATA

We are committed to protecting the privacy of children. For that reason, we do not knowingly collect or maintain Personal Information from any person we actually know is under the age of 18. The Service is not directed to individuals under the age of 18, and we request that these individuals not provide Personal Information through the Service. If your child has submitted Personal Information and you would like to request that such Personal Information be removed, please contact us as explained under the "Contacting Us" section.

## INDIVIDUALS WITH DISABILITIES

If you have a disability and believe that the format of any material on this website interferes with your ability to access the information, please contact us as explained under the "Contacting Us" section. To enable us to best assist you, please notify us in the first instance by including the following information: (1) the nature of the accessibility problem you experienced, (2) the web address (URL) of the requested material you tried to

access, (3) your preferred format in which you want to receive the material (electronic format, standard print, large print, etc.), and (4) your contact information so that we can work with you to address any accessibility issues you may have experienced. We will get back to you as soon as we can to address the requests and/or to provide the information you are seeking.

## UPDATES TO THIS PRIVACY POLICY

The Macitentan REMS may change this Privacy Policy. Any changes to this Privacy Policy will become effective when we post the revised Privacy Policy on the Service. Your use of the Service following these changes means that you accept the revised Privacy Policy. The Macitentan REMS recommends that you regularly review the Privacy Policy when you visit the Service. This policy was last updated on **March 13, 2023**.

## CONTACTING US

The Macitentan REMS and the Service is intended for and directed to U.S. residents only. This Privacy Policy is intended to apply to collection of information from residents of the United States. If you are not a resident of the United States, please be aware that your information may be transferred to, stored, and processed in the United States.

If you have any questions or concerns about this Privacy Policy, information handling practices, or any other aspect of privacy and security of your Personal Information, please call the Macitentan REMS at 1-888-572-2934.

## US SUPPLEMENTAL PRIVACY NOTICE

Last Updated **March 13, 2023**

This US Supplemental Privacy Notice ("Supplemental Notice") applies only to information collected about California, Colorado, Virginia, Utah, and Connecticut consumers. It provides information required under the following laws, (collectively, "US State Privacy Laws") and supplements the information contained in the Privacy Policy:

- California Consumer Privacy Act of 2018 and California Privacy Rights Act of 2020 (collectively, the "CPRA")
- Colorado Privacy Act of 2021 (the "CPA")
- Connecticut Data Privacy Act ("CTDPA")
- Utah Consumer Privacy Act of 2022 (the "UCPA")
- Virginia Consumer Data Protection Act of 2021 (the "VCDPA")

The Macitentan REMS also provides information collected about Nevada consumers under the heading "Privacy Notice for Nevada Residents" at the end of this Supplemental Notice. The other portions of this Supplemental Notice do not apply to Nevada consumers.

This Supplemental Notice describes Macitentan REMS (Risk Evaluation and Mitigation Strategy) Macitentan REMS ("Macitentan REMS") practices regarding the collection, use, and disclosure of Personal Information and provides instructions for submitting data subject requests.

Some portions of this Supplemental Notice apply only to consumers of particular states. In those instances, such language applies only to those consumers.



**Disclosure for California Consumers:** Unless specifically stated, The Macitentan REMS has not sold or shared Personal Information about California consumers to third parties for their own use in the past twelve months. Relatedly, the Macitentan REMS does not have actual knowledge that we sell or share Personal Information of California consumers under 16 years of age. However, the Macitentan REMS may share your Personal Information with our affiliates and trusted partners in arrangements that may meet the broad definition of “sale” or “share” under California law. In these arrangements, use of the information we share is limited by policies, contracts, or similar restrictions.

For purposes of the CPRA, a “sale” is the disclosure of Personal Information to a Third Party for monetary or other valuable consideration, and a “share” is the disclosure of Personal Information to a Third Party for cross-context behavioral advertising, whether or not for monetary or other valuable consideration.

**Disclosure for Colorado, Virginia, Utah, and Connecticut Consumers:** Unless specifically stated, the Macitentan REMS does not sell or share Personal Information to Third Parties for their own use. However, the Macitentan REMS may share or process one or more of the above categories of Personal Information with our affiliates and trusted partners in arrangements for purposes of targeted advertising, as the terms “sell,” “share,” “process,” and “targeted advertising” are defined in the CPA, VCDPA, UCPA, and CTDPA. In these arrangements, use of the information we share is limited by policies, contracts or similar restrictions.

## DATA SUBJECT RIGHTS

- **Exercising Data Subject Rights.** California, Colorado, Virginia Utah, and Connecticut consumers have certain rights with respect to the collection and use of their Personal Information. Those rights vary by state. As required by the CPRA, the Macitentan REMS provides detailed information below regarding the data subject rights available to California consumers. Colorado, Virginia, Utah, and Connecticut consumers have similar rights and can find more detail by referencing the applicable US State Privacy Laws.

You may exercise the data subject rights applicable to you under the applicable US State Privacy Laws by contacting our Privacy Office at the information listed in the “Contact Us” section below. While the Macitentan REMS will make reasonable efforts to accommodate your request, we reserve the right to impose certain restrictions or requirements on your request, if allowed by or required by applicable law.

Consumers in some states may also authorize an agent to make data subject requests on their behalf.

- **Verification of Data Subject Requests.** The Macitentan REMS may ask you to provide information that will enable the Macitentan REMS to verify your identity in order to comply with your data subject request. In particular, when a California or Connecticut consumer authorizes an agent to make a request on their behalf, we may require the agent to provide proof of signed permission from the consumer to submit the request, or we may require the consumer to verify their own identity to the Macitentan REMS or confirm with the Macitentan REMS that they provided the agent with permission to submit the request. In some instances, we may decline to honor your request if an exception applies under applicable law. The Macitentan REMS will respond to your request consistent with applicable law.
- **Non-Discrimination.** The Macitentan REMS will not discriminate against you for exercising your data subject rights. For example, we will not deny goods or services to you, or charge you different prices or rates, or provide a different level of quality for products or services as a result of you exercising your data subject rights.
- **Appeals** To appeal our decision on your data subject requests, you may contact the Macitentan REMS at the information listed in the “Contact Us” section below. Please enclose a copy of or otherwise specifically reference our decision on your data subject request, so that the Macitentan REMS may adequately address your appeal. We will respond to your appeal in accordance with applicable law.
- **Data Subject Rights Disclosure**

- **Right to Receive Information on Privacy Practices:** You have the right to receive the following information at or before the point of collection:
  - The categories of Personal Information to be collected;
  - The purposes for which the categories of Personal Information are collected or used;
  - Whether or not that Personal Information is sold or shared;
  - If the business collects Sensitive Personal Information, the categories of Sensitive Personal Information to be collected, the purposes for which it is collected or used, and whether that information is sold or shared; and
  - The length of time the business intends to retain each category of Personal Information, or if that is not possible, the criteria used to determine that period.

The Macitentan REMS has provided such information in this Supplemental Notice, and you may request further information about our privacy practices by contacting the Macitentan REMS as at the contact information provided below.

- **Right to Deletion:** You may request that the Macitentan REMS deletes any Personal Information about you that we collected from you.
- **Right to Correction:** You may request that the Macitentan REMS corrects any inaccurate Personal Information we maintain about you.
- **Right to Know:** You may request that the Macitentan REMS provides you with the following information about how we have handled your Personal Information in the 12 months preceding your request:
  - The categories of Personal Information we collected about you;
  - The categories of sources from which we collected such Personal Information;
  - The business or commercial purpose for collecting Personal Information about you;
  - The categories of Personal Information about you that we shared or disclosed and the categories of Third Parties with whom we shared or disclosed such Personal Information; and
  - The specific pieces of Personal Information we have collected about you.
- **Right to Receive Information About Onward Disclosures:** You may request that the Macitentan REMS discloses to you:
  - The categories of Personal Information that we have collected about you;
  - The categories of Personal Information that we have sold or shared about you and the categories of Third Parties to whom the Personal Information was sold or shared; and
  - The categories of Personal Information we have disclosed about you for a business purpose and the categories of persons to whom it was disclosed for a business purpose.
- **Right to Non-Discrimination:** You have the right not to be discriminated against for exercising your data subject rights. The Macitentan REMS will not discriminate against you for exercising your data subject rights.
- **Right to Restrict or Limit the Use of Sensitive Personal Information:** You have the right to restrict the use and disclosure of sensitive Personal Information to certain purposes related to the offering of goods or services as listed in the CPRA.
- **Right to Opt Out of Sharing, Disclosure, or Sale of Personal Information:** You have the right to direct the Macitentan REMS to not share, disclose, or sell your Personal Information. To exercise this right, you or your authorized representative may submit a request at the information listed in the "Contact Us" section below.



## YOUR NEVADA PRIVACY RIGHTS

Nevada law permits our users who are Nevada consumers to request that their Personal Information not be sold (as defined under applicable Nevada law), even if their Personal Information is not currently being sold. Requests may be made by calling the Macitentan REMS at 1-888-572-2934.

## OTHER DISCLOSURES

- **California Residents Under Age 18.** If you are a resident of California under the age of 18 and a registered user of our website, you may ask the Macitentan REMS to remove content or data that you have posted to the website by contacting the Macitentan REMS at the information listed in the “Contact Us” section below. Please note that your request does not ensure complete or comprehensive removal of the content or data, as, for example, some of your content or data may have been reposted by another user.
- **Disclosure About Direct Marketing for California Residents.** California Civil Code § 1798.83 permits California residents to annually request certain information regarding our disclosure of Personal Information to other entities for their direct marketing purposes in the preceding calendar year. The Macitentan REMS does not distribute your Personal Information to other entities for their own direct marketing purposes.
- **Financial Incentives for California Consumers.** Under California law, the Macitentan REMS may provide financial incentives to California consumers who allow the Macitentan REMS to collect, retain, sell, or share their Personal Information. The Macitentan REMS will describe such programs to you when we offer them to you.
- **Changes to our Supplemental Notice.** The Macitentan REMS reserves the right to amend this Supplemental Notice at our discretion and at any time. When we make material changes to this Supplemental Notice, we will notify you by posting an updated Supplemental Notice on our website and listing the effective date of such updates.
- **Contact Us.** If you have any questions, comments, requests, or concerns related to this Supplemental Notice, or how to access this policy in another format, please fax the Macitentan REMS at 1-833-681-0003 or call the Macitentan REMS at 1-888-572-2934.