

## Privacy Policy

Invincible Vision is committed to protecting the privacy of the registered members. We define personal information to include: name(s), email address, mailing address, survey responses, registration information and non-public information included in your correspondence with us.

When you contact Invincible Vision, your email address and other information included in your email may be forwarded to the appropriate person(s) within Invincible Vision for a response. A copy of your correspondence may be retained at the Invincible Vision office.

Invincible Vision will never release the mailing list of our registered members or the names of our member families to any outside organization or third party unless required to do so by law. However, if an outside organization sends us information for distribution to Invincible Vision members, we may post it on the Website or send it to you.

Information determined to be confidential can only be released by written or verbal permission by the subject of the information or organization that owns the information. Information may be released if required by law, such as in response to an investigation or subpoena. Invincible Vision Website provides links to other sites that may be of interest. Invincible Vision is not responsible for the privacy practices or content of other such web sites.

You must read this Privacy Policy (the "Privacy Policy") and the Website Terms and Conditions (the "Terms and Conditions") prior to using any portion of the Invincible Vision Website or Services located at [www.invinciblevision.org](http://www.invinciblevision.org). By using the Website, you agree to all the terms of the Privacy Policy and Terms and Conditions. If you do not agree with the terms of this Privacy Policy, you may not use any portion of the Website.

Invincible Vision respects your privacy and have written the Privacy Policy so that you are aware of the information the Invincible Vision collects from you, how that information is protected, and how it is used. If you have any questions or comments regarding the Privacy Policy, or you feel that Invincible Vision is not abiding by its posted Privacy Policy, please contact us at: [contact@invinciblevision.org](mailto:contact@invinciblevision.org).

### Purpose

This policy applies to Invincible Vision Website. This policy does not apply to internal activities (such as on intranets, applications, or interactions that do not involve the public).

This Privacy Policy outlines the type of information Invincible Vision collects from the registered members. We reserve the right to modify the Privacy Policy at any time, and without prior notice, by posting amended terms and conditions on the Invincible Vision Website. We encourage you to review the Privacy Policy periodically for any updates or changes.

### Collection, Use and Disclosure of Information

All of the information you provide to Invincible Vision will be maintained in a secure database, and any information that could identify you will not be shared without your express written consent, unless otherwise required by law.

De-identified data gathered may be made available to the members and users of the Website, and other third parties.

At any time, you have the right to withdraw your information from Invincible Vision. You may exercise this right by contacting the Invincible Vision at [contact@invinciblevision.org](mailto:contact@invinciblevision.org) and your account will be deactivated and the identifying information in your profile will be removed. Please note that any de-identified data accessed before your request for removal will however not be able to be retrieved.

### Protection of User Information

All users are required to review and abide by the Website Terms and Conditions and the Privacy Policy. We employ best practices from our networking to our secure servers to protect data from intrusion.

Where you use passwords, ID numbers, or other special access features on the Website, you should take special care to safeguard them.

The HIPAA privacy rules and HIPAA security rules mandate that covered entities have in place appropriate policies and procedures to protect the confidentiality and security of protected health information. In compliance with these regulations, the database security features of Invincible Vision target multiple levels including the data element (e.g., restricted access to fields), user (e.g., password authentication access), application (e.g., role-based access to features), and hosting services (e.g., firewall). Taken together, these features ensure access control, audit control, data integrity, user authentication, and transmission security. Administrative users of Invincible Vision ensure exported datasets are de-identified as defined in the HIPAA privacy regulation [45 C.F.R. §164.514 (b)(2)].

Invincible Vision de-identified data may be requested by physicians/study centers and other interested parties to conduct research on the prevalence of clinical manifestations and/or to determine numbers of registered members who may be eligible for participation in ongoing or upcoming studies or clinical trials. Such requests will be reviewed by the Invincible Vision Board. The Board will review requests for data, and such requests and approvals will be documented. Any individual listings provided to such external entities will not use any identifying information to protect the identity of members.

Member information may be stored by the Invincible Vision for an indefinite period of time.

### Ownership of Information

All of the information you provide to Invincible Vision in connection with the Website is owned by you. You agree to grant Invincible Vision the right to maintain, use and disclose your de-identified data as set forth in this Privacy Policy and Website Terms and Conditions. Your information may contribute to the development of inventions or commercial products from which others may derive economic benefit. You will have no rights to any inventions, commercial products or other such discoveries and you will receive no economic benefit.

## Website Links

The Invincible Vision Website may contain links to other web sites. This Privacy Policy applies solely to information collected on or submitted to the Invincible Vision Website. Invincible Vision is not responsible for the privacy practices of other sites linked on the Website. Invincible Vision encourages users to read the privacy policies of websites and third party advertisers when they connect to them through the Website.

## Communications from Invincible Vision

From time to time, the Invincible Vision, or other related entities may notify users of updates and other valuable information about the Invincible Vision and related clinical and research information. By using the Invincible Vision Website, or registering or subscribing for services provided on or through the Website, users consent to being contacted by the Invincible Vision, and to receiving such updates and information.

## Required Disclosures

You understand and agree that Invincible Vision may disclose information provided by you if in its good faith belief that such disclosure is required by applicable law.

## Contact Us; Member Accounts

If you elect to contact Invincible Vision through contact information provided on the Invincible Vision Website, or register for an account, you may be asked for any of the following: name, password, e-mail address, e-mail subject and a message containing your inquiry, and certain profile and account information. Invincible Vision stores this data in order to reply to the submitted inquiry or to establish and service the member account. The submitted information is then subject to the terms detailed in this Privacy Policy.

## Children Under The Age Of Thirteen (13)

Invincible Vision shall comply with the Children's Online Privacy Protection Act of 1998 (COPPA) which restricts the marketing of products and services online to children under 13. Invincible Vision is unable to prevent children under the age of thirteen (13) from visiting the Invincible Vision Website; however, no part of the Website is directed at or intended for persons under the age of thirteen (13). If you are under the age of thirteen (13), please do not access the Website at any time or in any manner. By providing personal identifiable information through the Website including, but not limited to, your name and e-mail address, you represent and warrant that you are at least at least eighteen (18) years of age and that you agree to comply with the Privacy Policy. If, at any time, Invincible Vision learns that personally identifiable information has been collected from persons under the age of thirteen (13) without parental or legally authorized representative consent, Invincible Vision will take the appropriate steps to delete such information.

## Change of Control

In the event that Invincible Vision is involved in a bankruptcy, merger, acquisition, reorganization or sale of assets, your information will not be sold or transferred as part of that transaction.

## Notification of Changes

You should review the Privacy Policy whenever you use the Website in order to be aware of the ways that your information is used. Invincible Vision reserves the right to change the Privacy Policy at any time, without prior notice.