

Privacy Policy of SOAR/The Hide & Seek Foundation

This Website collects some Personal Data from its Users.

Owner and Data Controller

The Hide & Seek Foundation/SOAR

6475 East Pacific Coast Highway
Suite 466
Long Beach, CA 90803
USA

Owner contact email: compliance@hideandseek.org

Types of Data collected

Among the types of Personal Data that this Website collects, by itself or through third parties, there are: first name; last name; email address; various types of Data; Usage Data; Trackers; answers to questions; clicks; keypress events; motion sensor events; mouse movements; scroll position; touch events; device information; number of Users; session statistics; state; city; physical address; company name; interaction events; page views; referral URL; operating systems; browser information; password; username.

Complete details on each type of Personal Data collected are provided in the dedicated sections of this privacy policy or by specific explanation texts displayed prior to the Data collection.

Personal Data may be freely provided by the User, or, in case of Usage Data, collected automatically when using this Website.

Unless specified otherwise, all Data requested by this Website is mandatory and failure to provide this Data may make it impossible for this Website to provide its services. In cases where this Website specifically states that some Data is not mandatory, Users are free not to communicate this Data without consequences to the availability or the functioning of the Service.

Users who are uncertain about which Personal Data is mandatory are welcome to contact the Owner.

Any use of Cookies – or of other tracking tools – by this Website or by the owners of third-party services used by this Website serves the purpose of providing the Service required by the User, in addition to any other purposes described in the present document and in the Cookie Policy.

Users are responsible for any third-party Personal Data obtained, published or shared through this Website.

Mode and place of processing the Data

Methods of processing

The Owner takes appropriate security measures to prevent unauthorized access, disclosure, modification, or unauthorized destruction of the Data.

The Data processing is carried out using computers and/or IT enabled tools, following organizational procedures and modes strictly related to the purposes indicated. In addition to the Owner, in some cases, the Data may be accessible to certain types of persons in charge, involved with the operation of this Website (administration, sales, marketing, legal, system administration) or external parties (such as third-party technical service providers, mail carriers, hosting providers, IT companies, communications agencies) appointed, if necessary, as Data Processors by the Owner. The updated list of these parties may be requested from the Owner at any time.

Place

The Data is processed at the Owner's operating offices and in any other places where the parties involved in the processing are located.

Depending on the User's location, data transfers may involve transferring the User's Data to a country other than their own. To find out more about the place of processing of such transferred Data, Users can check the section containing details about the processing of Personal Data.

Retention time

Unless specified otherwise in this document, Personal Data shall be processed and stored for as long as required by the purpose they have been collected for and may be retained for longer due to applicable legal obligation or based on the Users' consent.

The purposes of processing

The Data concerning the User is collected to allow the Owner to provide its Service, comply with its legal obligations, respond to enforcement requests, protect its rights and interests (or those of its Users or third parties), detect any malicious or fraudulent activity, as well as the following: Backup saving and management, Contacting the User, Displaying content from external platforms, Hosting and backend infrastructure, Infrastructure monitoring, SPAM protection, Tag Management, Traffic optimization and distribution, Handling payments, Advertising, Analytics, Collection of privacy-related preferences, Interaction with external social networks and platforms, Managing contacts and sending messages and Building and running this Website.

For specific information about the Personal Data used for each purpose, the User may refer to the section “Detailed information on the processing of Personal Data”.

Detailed information on the processing of Personal Data

Personal Data is collected for the following purposes and using the following services:

Advertising

This type of service allows User Data to be utilized for advertising communication purposes. These communications are displayed in the form of banners and other advertisements on this Website, possibly based on User interests. This does not mean that all Personal Data are used for this purpose. Information and conditions of use are shown below. Some of the services listed below may use Trackers to identify Users or they may use the behavioral retargeting technique, i.e. displaying ads tailored to the User’s interests and behavior, including those detected outside this Website. For more information, please check the privacy policies of the relevant services. Services of this kind usually offer the possibility to opt out of such tracking. In addition to any opt-out feature offered by any of the services below, Users may learn more on how to generally opt out of interest-based advertising within the dedicated section "How to opt-out of interest-based advertising" in this document.

Query Click (Query Click Limited)

Query Click is an advertising service provided by Query Click Limited.

Personal Data processed: Trackers; Usage Data.

Place of processing: United Kingdom – [Privacy Policy](#).

Analytics

The services contained in this section enable the Owner to monitor and analyze web traffic and can be used to keep track of User behavior.

Google Analytics 4 (Google LLC)

Google Analytics 4 is a web analysis service provided by Google LLC (“Google”). Google utilizes the Data collected to track and examine the use of this Website, to prepare reports on its activities and share them with other Google services. Google may use the Data collected to contextualize and personalize the ads of its own advertising network. In Google Analytics 4, IP addresses are used at collection time and then discarded before Data is logged in any data center or server. Users can learn more by consulting [Google’s official documentation](#).

Personal Data processed: number of Users; session statistics; Trackers; Usage Data.

Place of processing: United States – [Privacy Policy](#) – [Opt Out](#).

Backup saving and management

This type of service allows the Owner to save and manage backups of this Website on external servers managed by the service provider itself. The backups may include the source code and content as well as the data that the User provides to this Website.

Amazon Glacier (Amazon)

Amazon Glacier is a service to save and manage backups provided by Amazon Web Services Inc.

Personal Data processed: various types of Data as specified in the privacy policy of the service.

Place of processing: United States – [Privacy Policy](#).

Backup on Dropbox (Dropbox, Inc.)

Dropbox is a service to save and manage backups provided by Dropbox Inc.

Personal Data processed: various types of Data as specified in the privacy policy of the service.

Place of processing: United States – [Privacy Policy](#).

Building and running this Website

Key components of this Website are built and run directly by the Owner by making use of the software listed below.

WordPress (self-hosted) (this Website)

This Website is built and run by the Owner via a CMS software (Content Management System) called WordPress.

Personal Data processed: password; username.

Collection of privacy-related preferences

This type of service allows this Website to collect and store Users' preferences related to the collection, use, and processing of their personal information, as requested by the applicable privacy legislation.

iubenda Privacy Controls and Cookie Solution (iubenda srl)

The iubenda Privacy Controls and Cookie Solution allows the Owner to collect and store Users' preferences related to the processing of personal information, and in particular to the use of Cookies and other Trackers on this Website.

Personal Data processed: Trackers.

Place of processing: Italy – [Privacy Policy](#).

Contacting the User

Contact form (this Website)

By filling in the contact form with their Data, the User authorizes this Website to use these details to reply to requests for information, quotes or any other kind of request as indicated by the form's header.

Personal Data processed: email address; first name; last name; various types of Data.

Mailing list or newsletter (this Website)

By registering on the mailing list or for the newsletter, the User's email address will be added to the contact list of those who may receive email messages containing information of commercial or promotional nature concerning this Website. Your email address might also be added to this list as a result of signing up to this Website or after making a purchase.

Personal Data processed: city; company name; email address; first name; last name; physical address; state.

Displaying content from external platforms

This type of service allows you to view content hosted on external platforms directly from the pages of this Website and interact with them.

This type of service might still collect web traffic data for the pages where the service is installed, even when Users do not use it.

Google Fonts (Google LLC)

Google Fonts is a typeface visualization service provided by Google LLC that allows this Website to incorporate content of this kind on its pages.

Personal Data processed: Trackers; Usage Data.

Place of processing: United States – [Privacy Policy](#).

YouTube video widget (Google LLC)

YouTube is a video content visualization service provided by Google LLC that allows this Website to incorporate content of this kind on its pages.

Personal Data processed: Trackers; Usage Data.

Place of processing: United States – [Privacy Policy](#).

YouTube Data API (Google LLC)

YouTube Data API is a video content visualization service provided by Google LLC that allows this Website to incorporate functions normally executed on YouTube so that Users can watch, find, and manage YouTube content directly on this Website.

Through this Service, this Website may collect Data directly or indirectly on or from Users' devices, including by making use of Trackers. Users may restrict such access to their Data via the [security settings page](#) provided by Google. Users may ask the Owner for further information about these privacy settings at any time through the contact details provided in this document.

Data collected through the Service may also be used to help third parties deliver interest-based advertising. Users can opt out of third-party interest-based advertising through their device settings or by visiting the [Network Advertising Initiative opt-out page](#).

Personal Data processed: device information.

Place of processing: United States – [Privacy Policy](#) – [Opt out](#).

Handling payments

Unless otherwise specified, this Website processes any payments by credit card, bank transfer or other means via external payment service providers. In general and unless where otherwise stated, Users are requested to provide their payment details and personal information directly to such payment service providers. This Website isn't involved in the collection and processing of such information: instead, it will only receive a notification by the relevant payment service provider as to whether payment has been successfully completed.

Donations

You can make a contribution to SOAR and help find a cure for Niemann Pick Type C by clicking here or by sending your contribution to:

The Hide & Seek Foundation/SOAR
6475 East Pacific Coast Highway
Suite 466
Long Beach, CA 90803
USA

By clicking on the DONATE tab of this website, you are redirected to the Donation Page of the Hide & Seek Foundation, which is affiliated with SOAR. Please see the privacy policy of <https://hideandseek.org/privacy-policy/>. Payments comply with Stripe's Payment Processor system using Strong Customer Authentication (SCA/PSD2).

Hosting and backend infrastructure

This type of service has the purpose of hosting Data and files that enable this Website to run and be distributed as well as to provide a ready-made infrastructure to run specific features or parts of this Website.

Some services among those listed below, if any, may work through geographically distributed servers, making it difficult to determine the actual location where the Personal Data are stored.

Amazon Web Services (AWS) (Amazon Web Services, Inc.)

Amazon Web Services (AWS) is a hosting and backend service provided by Amazon Web Services, Inc.

Personal Data processed: various types of Data as specified in the privacy policy of the service.

Place of processing: United States – [Privacy Policy](#); Canada – [Privacy Policy](#); Brazil – [Privacy Policy](#).

accessiBe accessWidget (accessiBe Ltd.)

accessiBe accessWidget is a service that helps websites to comply with accessibility standards and is provided by accessiBe Ltd.

Personal Data processed: browser information; clicks; device information; interaction events; operating systems; page views; referral URL; Usage Data.

Place of processing: Israel – [Privacy Policy](#).

Infrastructure monitoring

This type of service allows this Website to monitor the use and behavior of its components so its performance, operation, maintenance and troubleshooting can be improved.

Which Personal Data are processed depends on the characteristics and mode of implementation of these services, whose function is to filter the activities of this Website.

Uptime Robot (Buzpark Bilisim Tarim Urunleri Sanayi Tic. Ltd. Sti.)

Uptime Robot is a monitoring service provided by Buzpark Bilisim Tarim Urunleri Sanayi Tic. Ltd. Sti.

Personal Data processed: various types of Data as specified in the privacy policy of the service.

Place of processing: Turkey – [Privacy Policy](#).

Interaction with external social networks and platforms

This type of service allows interaction with social networks or other external platforms directly from the pages of this Website. The interaction and information obtained through this Website are always subject to the User's privacy settings for each social network.

This type of service might still collect traffic data for the pages where the service is installed, even when Users do not use it. It is recommended to log out from the respective services in order to make sure that the processed data on this Website isn't being connected back to the User's profile.

Facebook Like button and social widgets (Meta Platforms, Inc.)

The Facebook Like button and social widgets are services allowing interaction with the Facebook social network provided by Meta Platforms, Inc.

Personal Data processed: Trackers; Usage Data.

Place of processing: United States – [Privacy Policy](#).

LinkedIn button and social widgets (LinkedIn Corporation)

The LinkedIn button and social widgets are services allowing interaction with the LinkedIn social network provided by LinkedIn Corporation.

Personal Data processed: Trackers; Usage Data.

Place of processing: United States – [Privacy Policy](#).

Managing contacts and sending messages

This type of service makes it possible to manage a database of email contacts, phone contacts or any other contact information to communicate with the User.

These services may also collect data concerning the date and time when the message was viewed by the User, as well as when the User interacted with it, such as by clicking on links included in the message.

Amazon Simple Email Service (SES) (Amazon)

Amazon Simple Email Service is an email address management and message sending service provided by Amazon.com Inc.

Personal Data processed: email address.

Place of processing: United States – [Privacy Policy](#).

SPAM protection

This type of service analyzes the traffic of this Website, potentially containing Users' Personal Data, with the purpose of filtering it from parts of traffic, messages and content that are recognized as SPAM.

Google reCAPTCHA (Google LLC)

Google reCAPTCHA is a SPAM protection service provided by Google LLC.
The use of reCAPTCHA is subject to the Google [privacy policy](#) and [terms of use](#).

Personal Data processed: answers to questions; clicks; keypress events; motion sensor events; mouse movements; scroll position; touch events; Trackers; Usage Data.

Place of processing: United States – [Privacy Policy](#).

Tag Management

This type of service helps the Owner to manage the tags or scripts needed on this Website in a centralized fashion.
This results in the Users' Data flowing through these services, potentially resulting in the retention of this Data.

Google Tag Manager (Google LLC)

Google Tag Manager is a tag management service provided by Google LLC.

Personal Data processed: Trackers.

Place of processing: United States – [Privacy Policy](#).

Traffic optimization and distribution

This type of service allows this Website to distribute their content using servers located across different countries and to optimize their performance.

Which Personal Data are processed depends on the characteristics and the way these services are implemented. Their function is to filter communications between this Website and the User's browser.

Considering the widespread distribution of this system, it is difficult to determine the locations to which the contents that may contain Personal Information of the User are transferred.

Sucuri CloudProxy (Sucuri, Inc.)

Sucuri CloudProxy is a traffic optimization and distribution service provided by Sucuri, Inc.
The way Sucuri CloudProxy is integrated means that it filters all the traffic through this Website, i.e., communication between this Website and the User's browser, while also allowing analytical data from this Website to be collected.

Personal Data processed: various types of Data as specified in the privacy policy of the service.

Place of processing: United States – [Privacy Policy](#).

Information on opting out of interest-based advertising

In addition to any opt-out feature provided by any of the services listed in this document, Users may learn more on how to generally opt out of interest-based advertising within the dedicated section of the Cookie Policy.

Further information about the processing of Personal Data

Selling goods and services online

The Personal Data collected are used to provide the User with services or to sell goods, including payment and possible delivery.
The Personal Data collected to complete the payment may include the credit card, the bank account used for the transfer, or any other means of payment envisaged. The kind of Data collected by this Website depends on the payment system used.

Analysis and predictions based on the User's Data ("profiling")

The Owner may use the Personal and Usage Data collected through this Website to create or update User profiles. This type of Data processing allows the Owner to evaluate User choices, preferences and behaviour for the purposes outlined in the respective section of this document.

User profiles can also be created through the use of automated tools like algorithms, which can also be provided by third parties.
To find out more about the profiling activities performed, Users can check the relevant sections of this document.

The User always has a right to object to this kind of profiling activity. To find out more about the User's rights and how to exercise them, the User is invited to consult the section of this document outlining the rights of the User.

Automated decision-making

Automated decision-making means that a decision which is likely to have legal effects or similarly significant effects on Users, is taken solely by technological means, without any human intervention. This Website may use the Users' Personal Data to make decisions entirely or partially based on automated processes according to the purposes outlined in this document. This Website adopts automated decision-making processes as far as necessary to enter into or perform a contract between Users and Owner, or on the basis of the Users' explicit consent, where such consent is required by the law.

Automated decisions are made by technological means – mostly based on algorithms subject to predefined criteria – which may also be provided by third parties.

The rationale behind automated decision-making is:

- to enable or otherwise improve the decision-making process;
- to grant Users fair and unbiased treatment based on consistent and uniform criteria;
- to reduce the potential harm derived from human error, personal bias and the like which may potentially lead to discrimination or imbalance in the treatment of individuals etc.;
- to reduce the risk of Users' failure to meet their obligation under a contract. To find out more about the purposes, the third-party services, if any, and any specific rationale for automated decisions used within this Website, Users can check the relevant sections in this document.

Consequences of automated decision-making processes for Users and rights of Users subjected to it

As a consequence, Users subject to such processing, are entitled to exercise specific rights aimed at preventing or otherwise limiting the potential effects of the automated decisions taken.

In particular, Users have the right to:

- obtain an explanation about any decision taken as a result of automated decision-making and express their point of view regarding this decision;
- challenge a decision by asking the Owner to reconsider it or take a new decision on a different basis;
- request and obtain from the Owner human intervention on such processing.

To learn more about the Users' rights and the means to exercise them, Users are invited to consult the section of this document relating to the rights of Users.

Equal protection of User Data

This Website shares User Data only with third parties carefully selected to ensure that they provide the same or equal protection of User Data as stated in this privacy policy and requested by applicable data protection laws. Further information on data processing and privacy practices by third parties can be found in their respective privacy policies.

localStorage

localStorage allows this Website to store and access data right in the User's browser with no expiration date.

Preference Cookies

Preference Cookies store the User preferences detected on this Website in the local domain such as, for example, their timezone and region.

Rights for registered California Users under the age of 18

California's "Online Eraser" law, part of California's Business and Professions Code Sections 22580-22582, requires operators of certain websites and online services targeting minors to allow registered Users who are under the age of 18 and residents of California to request removal of content they post.

If a registered User fits that description and posted content on this Website, they may request removal of such content by contacting the Owner or its privacy policy coordinator at the contact details provided in this document.

In response to this request, the Owner may make content posted by the registered User invisible to other registered Users and the public (rather than deleting it entirely), in which case the content may remain on the Owner's servers. It may also be publicly available elsewhere if a third party copied and reposted this content.

The Service is intended for adults

Users declare themselves to be adult according to their applicable legislation. Minors may not use this Website.

Cookie Policy

This Website uses Trackers. To learn more, Users may consult the [Cookie Policy](#).

Further Information for Users

Legal basis of processing

The Owner may process Personal Data relating to Users if one of the following applies:

- Users have given their consent for one or more specific purposes.
- provision of Data is necessary for the performance of an agreement with the User and/or for any pre-contractual obligations thereof;
- processing is necessary for compliance with a legal obligation to which the Owner is subject;
- processing is related to a task that is carried out in the public interest or in the exercise of official authority vested in the Owner;
- processing is necessary for the purposes of the legitimate interests pursued by the Owner or by a third party.

In any case, the Owner will gladly help to clarify the specific legal basis that applies to the processing, and in particular whether the provision of Personal Data is a statutory or contractual requirement, or a requirement necessary to enter into a contract.

Further information about retention time

Unless specified otherwise in this document, Personal Data shall be processed and stored for as long as required by the purpose they have been collected for and may be retained for longer due to applicable legal obligation or based on the Users' consent.

Therefore:

- Personal Data collected for purposes related to the performance of a contract between the Owner and the User shall be retained until such contract has been fully performed.
- Personal Data collected for the purposes of the Owner's legitimate interests shall be retained as long as needed to fulfill such purposes. Users may find specific information regarding the legitimate interests pursued by the Owner within the relevant sections of this document or by contacting the Owner.

The Owner may be allowed to retain Personal Data for a longer period whenever the User has given consent to such processing, as long as such consent is not withdrawn. Furthermore, the Owner may be obliged to retain Personal Data for a longer period whenever required to fulfil a legal obligation or upon order of an authority.

Once the retention period expires, Personal Data shall be deleted. Therefore, the right of access, the right to erasure, the right to rectification and the right to data portability cannot be enforced after expiration of the retention period.

The rights of Users based on the General Data Protection Regulation (GDPR)

Users may exercise certain rights regarding their Data processed by the Owner.

In particular, Users have the right to do the following, to the extent permitted by law:

- **Withdraw their consent at any time.** Users have the right to withdraw consent where they have previously given their consent to the processing of their Personal Data.
- **Object to processing of their Data.** Users have the right to object to the processing of their Data if the processing is carried out on a legal basis other than consent.
- **Access their Data.** Users have the right to learn if Data is being processed by the Owner, obtain disclosure regarding certain aspects of the processing and obtain a copy of the Data undergoing processing.
- **Verify and seek rectification.** Users have the right to verify the accuracy of their Data and ask for it to be updated or corrected.
- **Restrict the processing of their Data.** Users have the right to restrict the processing of their Data. In this case, the Owner will not process their Data for any purpose other than storing it.
- **Have their Personal Data deleted or otherwise removed.** Users have the right to obtain the erasure of their Data from the Owner.
- **Receive their Data and have it transferred to another controller.** Users have the right to receive their Data in a structured, commonly used and machine readable format and, if technically feasible, to have it transmitted to another controller without any hindrance.
- **Lodge a complaint.** Users have the right to bring a claim before their competent data protection authority.

Users are also entitled to learn about the legal basis for Data transfers abroad including to any international organization governed by public international law or set up by two or more countries, such as the UN, and about the security measures taken by the Owner to safeguard their Data.

Details about the right to object to processing

Where Personal Data is processed for a public interest, in the exercise of an official authority vested in the Owner or for the purposes of the legitimate interests pursued by the Owner, Users may object to such processing by providing a ground related to their particular situation to justify the objection.

Users must know that, however, should their Personal Data be processed for direct marketing purposes, they can object to that processing at any time, free of charge and without providing any justification. Where the User objects to processing for direct marketing purposes, the Personal Data will no longer be processed for such purposes. To learn whether the Owner is processing Personal Data for direct marketing purposes, Users may refer to the relevant sections of this document.

How to exercise these rights

Any requests to exercise User rights can be directed to the Owner through the contact details provided in this document. Such requests are free of charge and will be answered by the Owner as early as possible and always within one month, providing Users with the information required by law. Any rectification or erasure of Personal Data or restriction of processing will be communicated by the Owner to each recipient, if any, to whom the Personal Data has been disclosed unless this proves impossible or involves disproportionate effort. At the Users' request, the Owner will inform them about those recipients.

Additional information about Data collection and processing

Legal action

The User's Personal Data may be used for legal purposes by the Owner in Court or in the stages leading to possible legal action arising from improper use of this Website or the related Services.

The User declares to be aware that the Owner may be required to reveal personal data upon request of public authorities.

Additional information about User's Personal Data

In addition to the information contained in this privacy policy, this Website may provide the User with additional and contextual information concerning particular Services or the collection and processing of Personal Data upon request.

System logs and maintenance

For operation and maintenance purposes, this Website and any third-party services may collect files that record interaction with this Website (System logs) or use other Personal Data (such as the IP Address) for this purpose.

Information not contained in this policy

More details concerning the collection or processing of Personal Data may be requested from the Owner at any time. Please see the contact information at the beginning of this document.

Changes to this privacy policy

The Owner reserves the right to make changes to this privacy policy at any time by notifying its Users on this page and possibly within this Website and/or - as far as technically and legally feasible - sending a notice to Users via any contact information available to the Owner. It is strongly recommended to check this page often, referring to the date of the last modification listed at the bottom.

Should the changes affect processing activities performed on the basis of the User's consent, the Owner shall collect new consent from the User, where required.

Definitions and legal references

Personal Data (or Data)

Any information that directly, indirectly, or in connection with other information — including a personal identification number — allows for the identification or identifiability of a natural person.

Usage Data

Information collected automatically through this Website (or third-party services employed in this Website), which can include: the IP addresses or domain names of the computers utilized by the Users who use this Website, the URI addresses (Uniform Resource Identifier), the time of the request, the method utilized to submit the request to the server, the size of the file received in response, the numerical code indicating the status of the server's answer (successful outcome, error, etc.), the country of origin, the features of the browser and the operating system utilized by the User, the various time details per visit (e.g., the time spent on

each page within the Application) and the details about the path followed within the Application with special reference to the sequence of pages visited, and other parameters about the device operating system and/or the User's IT environment.

User

The individual using this Website who, unless otherwise specified, coincides with the Data Subject.

Data Subject

The natural person to whom the Personal Data refers.

Data Processor (or Processor)

The natural or legal person, public authority, agency or other body which processes Personal Data on behalf of the Controller, as described in this privacy policy.

Data Controller (or Owner)

The natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of Personal Data, including the security measures concerning the operation and use of this Website. The Data Controller, unless otherwise specified, is the Owner of this Website.

This Website (or this Application)

The means by which the Personal Data of the User is collected and processed.

Service

The service provided by this Website as described in the relative terms (if available) and on this site/application.

European Union (or EU)

Unless otherwise specified, all references made within this document to the European Union include all current member states to the European Union and the European Economic Area.

Cookie

Cookies are Trackers consisting of small sets of data stored in the User's browser.

Tracker

Tracker indicates any technology - e.g Cookies, unique identifiers, web beacons, embedded scripts, e-tags and fingerprinting - that enables the tracking of Users, for example by accessing or storing information on the User's device.

Legal information

This privacy policy relates solely to this Website, if not stated otherwise within this document.

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