

PID GENIUS PRIVACY POLICY

IPOPI, the International Patient Organisation for Primary Immunodeficiencies, is the Association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID).

This document is drawn up in order to meet the transparency obligations to the data subjects with respect to the processing of personal data dependent on the use of PID Genius (hereinafter also "APP").

Prior to using the APP PID Genius, the User declares to have read and accepted this Privacy Policy and the APP General Terms and Conditions of Use.

Data controller

IPOPI UK office, Rocky Bottom, Trerieve, Dowlerry Cornwall PL11 3LY United Kingdom;

Email: pidgenius@ipopi.org

Phone: +351 21 407 5720

Why is PID Genius collecting personal data?

The APP uses your personal identification data	Such data allow you to identify yourself directly (e.g. name, surname, date of birth, email address, tax code or equivalent).	Processing of this data is necessary to comply with your request for registration to PID Genius and for using the APP.	
The APP uses your potentially identifiable personal data	Personal data such as the on-line identification number or device data you use to connect to the APP.	The processing of these data directly affects the concrete and effective use of the APP.	
APP uses data stored by your device (tracking elements)	Personal data are essentially those stored by the device during the login sessions and the using of the APP.	Google Analytics Firebase is used to understand how the APP is utilized by you. This is a technical tool used to ensure you have a better experience of using the service through the APP.	N.B. No procedure is envisaged and no procedure which involves the possibility of automated production, decisions of legal effects that affect you or affect significantly the same about your person, including profiling, will be implemented.
The APP uses personal information about your health	These are personal data that can reveal information related to your physical / mental health, past, present or future	Processing of such data is only eventual, in fact it happens only when you decide to upload them to the APP. In any case, the processing of these data will be geared towards ensuring specific requirements that apply to you and, in the end, you will be required explicit consent to the use of services and the implementation of functionalities that imply the management of your personal health data.	Your data will not be processed for direct marketing purposes.

Why are we processing your data?

Account registration	Your personal identifying data are processed in accordance with the obligations arising out of the terms and condition of use you have applied to by choosing and using the APP.	
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Management of functionalities and services	Your personal data (identifiable and potentially such) are processed in accordance with the obligations arising out of the terms and condition of use you have subscribed and to fulfil the related obligation, especially on security, of the data controller.	
Further Treatments (Health Data)	Your data can be processed only with your explicit consent, clearly expressed also through procedures provided by the APP.	You may revoke consent by using the specific link present in the APP for this purpose. The revocation does not affect the legality of the treatment based on consent given before the same.
Further Treatments (Other data)	Your data can be processed only with your explicit consent, clearly expressed also through procedures provided by the APP.	You may revoke consent by using the same procedure for this purpose as a guarantee of its explicit expression. The revocation does not affect the legality of the treatment based on consent given before the same.
Further treatment (communication with other data controllers)	Communication is permitted due to legal purposes and legal considerations that have just been considered against public law bodies, social networking services possibly associated with the service, affiliated app stores and developers, affiliated companies or associations from legal constraints to the data controller.	I remind you that any activity performed on your data, including their communication, it will be aimed at treatment other than that declared and still descendants inevitably by these. Processing for direct marketing or profiling purposes are expressly excluded.
Data retention	Any processing is carried out in compliance with the security measures provided by the data controller, also by its processor(s), to guarantee the confidentiality and integrity of your personal data, for the time necessary to meet the purposes pursued by the service provided by APP.	<p>The retention period varies depending on the data processed and the fact that over time the processed data allow us to guarantee your identification:</p> <p>Identification Data: Until the dissolution of the relationship and the expiration of the purposes of the treatment resulting from any cause, except for further purposes that exceed the retention period when they meet certain statutory obligations (e.g. accountings);</p> <p>personal data to reveal the state of health: until the dissolution of the relationship and the end of any processing, unless the consent is withdrawn even though it has been consciously lent;</p> <p>Potentially identifiable personal data: until the dissolution of the relationship and the expiration of the purpose of the treatment resulting therefrom, without further purpose beyond the retention period when they meet certain legal obligations (e.g. security and communication and notification of data breaches to the</p>

		<p>competent control or judicial authority, according to any applicable law);</p> <p>Further data: processing of these data may be interrupted following the revocation of the consent even though they are deliberately lent.</p> <p>However, you are entitled to the rights that are recognized by any applicable law.</p>
Data transfer	<p>No data will be transfer and processed to any country outside of E.U. or any international organization. In any case, the transfer of personal data subject to processing or intended to be processed after transfer to a country outside E.U. or an international organization, including subsequent transfer of personal data from a third country or an international organization to another third country or a third country's other international organization, takes place in compliance with the conditions for the purpose provided for by any applicable law.</p>	

The APP allows you to manage your information and your choices also in relation to the exercise of the rights that the applicable law recognizes you, essentially through its capabilities you are guaranteed to:

- revoke consent when it is lent;
- access your data at any time and / or exercise your right of access under the applicable law, sending your request to pidgenius@ipopi.org. This allows you to request the rectification, blocking, deletion and final deletion of your data, except in cases where the applicable law provides for the possibility of differentiating, suspending or even excluding the exercise;
- exercise, pursuant to the applicable law, other rights that concern you, such as opposing the processing of your data or limiting it, with the exception of the foreseen exceptions;
- exercise, pursuant to the applicable law, the right to the portability of your data by submitting a request in order to receive them as well as to transmit them to a different data controller;
- know how to apply to any competent authority, judicial or not, in order to assert your rights.

How is the processing done?

The App may access your data for security reasons, in such a case also by processor(s) identified in accordance with the applicable law, in order to verify potential violations and update its functionality in order to increase its consistent security with any measures that the applicable legislation should consider in a more appropriate and reliable manner; in order also to verify the adequacy of the measures applied to exclude, limit and / or contain the risks for the confidentiality and integrity of the data processed; finally, to identify, analyse, prevent and manage fraud and other illegal activities or technical or security issues.

The APP will present the information you are interested in, even when up-to-date. You will be allowed to verify, if necessary, the different versions that will be released.