

EU-IPFF Privacy Policy

This Privacy and Cookies Policy outlines what EU-IPFF does with your personal information that we collect when you visit our website or receive our newsletter. In the context of these activities, we collect, hold, disclose and/or otherwise process personal data. We also place cookies on your computer or device.

We therefore encourage you to read this Privacy and Cookies Policy carefully. For your convenience, information about your privacy is included in Part 1 and specific information about the cookies we use and how you can manage them is included in Part 2.

From time to time, we may need to change this Privacy and Cookies Policy. The most recent version of this Policy is at all times available on our official website.

PART 1: PRIVACY AND PERSONAL DATA

At EU-IPFF, we value your right to privacy and make every effort to protect your personal data in accordance with applicable data protection legislation and more specifically with the General Data Protection Regulation (“GDPR”).

For your complete information, EU-IPFF AISBL (the European Idiopathic Pulmonary Fibrosis and Related Disorders Federation) is an organisation that brings together European national patient associations committed to defending their vision of equal access to treatment and care for all patients living with Idiopathic Pulmonary Fibrosis (IPF), regardless of geography, socio-economic status or age. EU-IPFF AISBL has its address at Jules de Cocklaan 95, 9050 Gentbrugge, Belgium and it is registered in Belgium under the number 0662.459.817.

We collect the following information regarding you or your device:

- Your email address, first name and last name when you sign up for our newsletter.
- Information we receive via Google Analytics or other cookies (see PART 2 below) whilst you use our website. This may include: IP addresses, preferences, web pages you visited prior to coming to our or our Users’ sites, information about your browser, network or device (such as browser type and version, operating system, internet service provider, preference settings, unique device IDs and language and other regional settings), information about how you interact with pages on our website (such as timestamps, clicks, scrolling, browsing times, searches, transactions, referral pages, load times, and problems you may encounter, such as loading errors).

We collect personal information by:

- You providing us with your personal information directly (e.g. registering for our newsletter),

- We record some information automatically when you use our website (e.g. through cookies and Google Analytics – see PART 2 below).

We use personal information for:

- Customer communication and direct marketing. We will only contact you to provide you with updates on the EU-IPFF activities and events; by sending you newsletters for example.
- Service improvement. By using cookies and tracking details via Google Analytics we can improve and customize our services based on our customer's location, for example (for more specific information, see PART 2 below).

Our data processing activities are based on our legitimate interest to defend the rights of IPF patients at European level. EU-IPFF supports an immediate and sustainable improvement of the quality of life and overall survival of IPF patients, and of patients suffering from other interstitial lung diseases.

For the processing of your personal data for electronic direct marketing purposes (our electronic newsletter), we rely upon your opt-in consent. Only if you have unambiguously stated that you would like to receive our electronic newsletter (you are entirely free to do this), we will register you for our electronic mailings. Note that you have the right to withdraw that consent at any time, free of charge, and without this having any negative implications for you. You may do so by e-mail (secretariat@eu-ipff.org) or via the opt-out link included in each of our marketing mailings.

For the setting of non-technical cookies (tracking and analytical cookies, see PART 2 below), we will also rely on your unambiguous consent, obtained through a cookies consent banner.

We share your personal information with:

- Service providers. We share personal information with our service providers (IT/cloud service providers or PR/marketing agencies) that act as our 'processors'.
- We will not share your data with any other third parties and we will never sell your personal data to any third party.

We will implement appropriate safeguards when transferring your personal data to third parties. If necessary, we will conclude a data transfer or a data processing agreement.

We store personal information:

- For marketing purposes. The precise periods for which we keep your personal information vary depending on the nature of the information and why we need it.
- Securely in our databases and on marketing tool providers such as MailChimp.

We will ensure that your personal data will not be stored for longer than is necessary in relation to the purposes for which we process these data (see above). Afterwards it is still possible that your data can be found in our back-ups or archives, but they will no longer be actively processed in a file. Only where we are legally obliged to, or where this is necessary for defending our interests in the context of judicial proceedings (e.g. in case of a dispute), we may store the personal data for a longer period. For specific retention periods regarding the cookies we use, see PART 2 below.

Also, as soon as we note that your contact details are no longer accurate or active, or whenever you decide to use your unsubscribe right, we will no longer keep your personal data for these purposes.

More information on our retention periods is available upon simple request by e-mailing secretariat@eu-ipff.org.

We respect your legal rights:

Within the limits defined by articles 15-22 of the GDPR, you have the statutory right to:

- receive information about and access your personal data;
- rectify your personal data;
- erasure of your personal data ('right to be forgotten');
- request restriction of processing of your personal data;
- object to the processing of your personal data (in particular to unsubscribe from our electronic newsletter);
- receive your personal data in a structured, commonly used and machine readable format and to (have) transmit(ted) your personal data to another organisation; and
- to lodge a complaint relating to the processing of your personal data by us with the data protection authority in your country.

In principle, you may exercise these rights free of charge. Only where requests are manifestly unfounded or excessive we may charge a reasonable fee. We aim to respond as quickly as possible to your requests or questions. We might request a proof of identity in advance in order to double-check your request.

Further information and advice about your rights can be obtained from the data protection authority in your country.

If you have any other questions or concerns about this Privacy Policy or the processing of your personal data by us, please feel free to contact us by sending an e-mail to secretariat@eu-ipff.org or by writing to the address mentioned above.

PART 2: COOKIES

Information on cookies used on our website

We use certain cookies on our website. Cookies are small pieces of data that are stored on your computer or mobile device via your browser. Some of them are essential to make our website work, others serve to provide you a better, faster and safer user experience.

Below you can find a complete list of the cookies that we are using:

Name	Type	Ownership	Storage
ss_cpvisit	Analytics & Performance	Squarespace	2 years
ss_cvvisit	Analytics & Performance	Squarespace	30 minutes
ss_cid	Analytics & Performance	Squarespace	2 years
ss_cvt	Analytics & Performance	Squarespace	30 minutes
ss_cvr	Analytics & Performance	Squarespace	2 years
crumb	Functional & Required	Squarespace	Session
MCPopupClosed	Functional & Required	Squarespace	Persistent
ss_cookieallowed	Analytics & Performance	Squarespace	30 days

How can you manage / delete these cookies?

All major internet browsers offer the option to manage the cookies that were installed on your computer or mobile device. In case you do not want this website to place cookies on your computer or mobile device, you may limit or delete these easily by adjusting you mobile or browser settings.

In addition, you can set you mobile or browser settings in such a way that you get a notification every time you receive a cookie on your computer or mobile device, so that you can decide whether you wish to accept this cookie or not.

Please do note that when you disable certain cookies of which we are making use, the possibility exists that certain parts of our website will no longer function properly and you will no longer enjoy an optimal user experience.