

International Network for Fatty Acid Oxidation Research and Management (INFORM)

INFORM is based out of the UPMC Children's Hospital of Pittsburgh
Medical Genetics, Faculty Pavilion, 4401 Penn Ave. Pittsburgh, PA 15224

We operate within the requirements of the EU General Data Protection Regulations 2018 and other electronic marketing legislation. We work within the principles of fair data processing, namely:

- Using information in a way that people would reasonably expect
- Thinking about the impact of our processing
- Being transparent and ensuring that people know how we'll use their information.

This statement, which may be amended from time to time by updates on this page, sets out the basis on which any personal data we collect from you, or that you provide to us, will be processed by us, as data controller and a data processor. Please read the following carefully to understand our views and practices regarding your personal data and how we will treat it.

What this Privacy Statement covers

This statement covers how we treat any personal information that we collect and receive either from our website or as part of our broader operating processes.

We do not sell or pass on any personal information about our clients or prospects and we only use any information shared with us for running and improving our services and in that capacity operate as a data controller and, to the extent that we process the data, as a data processor.

This statement tells you what information we collect, the steps we take to protect and secure it, how we use and share information, and finally, how you can contact us with questions or concerns.

Information we collect

- (a) Personal Information.** We collect personal information (e.g., name, email address, phone number, etc.) when you:
- Sign up to our newsletter
 - Send us an enquiry through our website*
 - Email us
 - Work with us as a customer, supplier or employee
 - Exhibit at an event where we are appointed to organise and / or manage operations and "official contractor" services
 - Sign-up to participate / attend an event where we are appointed to manage the registration process

*Note: This website is not intended for children and we do not knowingly collect data relating to children.

We also maintain a simple prospect database justified under a Legitimate Interest assessment where we collate names and contact details of B2B decision makers who are known buyers of our type of service.

- (b) Other User Information.** When you access and use our services, we may collect additional contextual information about your company as well as your design and

aesthetics preferences. We do not link this additional data to any other information we collect about you and do not undertake any profiling activity from this type of data.

- (c) Billing Information.** If you contract us for event services, we will require your billing information in order to process the transaction. Billing information includes your name, address, telephone number, credit, debit or bank details and other information necessary to process the transaction.

We do not store credit card numbers; this information is discarded after your transaction has been processed.

- (d) Use of our website.** The personal data or personal information we collect about you is made up of the information you give us or from which you can be identified during the use of the website and our communications with you.

You can access and browse our website without disclosing your personal data. However, there are some exceptions to this which are detailed below.

Our website uses email for visitors to request or share information with us. We collect visitor contact information (i.e. name, email address and phone numbers) and unique identifiers (if applicable).

Our website does not enable our visitors to communicate with others or to post information to be accessed by others.

- (e) IP Addresses and Cookies.** We may collect information about your computer, including where available your IP address, operating system and browser type, for system administration. This is statistical data about our users' browsing actions and patterns and does not identify any individual. For the same reason, we may obtain information about your general internet usage by using a cookie file which is stored on the hard drive of your computer.

Uses made of the information

We use this information held about you in the following ways:

- To ensure that content from our site is presented in the most effective manner to you and to your computer
- To provide you with information, products or services that you request from us or which we feel may interest you, where you have consented to be contacted for such purposes
- To allow you to participate in interactive features of our service, when you choose to do so
- To cross reference information you have supplied with information supplied by our client for purposes of verifying whether you are an authorised user
- To notify you about changes to our service.

We may also contact you by email, post or telephone. Please note that where you have provided sensitive data to us, we shall only use your sensitive data for the purpose for which the data was provided to us.

You have the right to withdraw consent to marketing at any time by using the 'unsubscribe' or 'opt-out' mechanism on any emails we send you or by sending an email to keith.mcintire@chp.edu (see also below). We strive to provide you with choices regarding certain personal data uses, particularly around marketing and advertising.

We have set out below, in a table format, a description of all the ways we plan to use your personal data, and which of the legal bases we rely on to do so. We have also identified what our legitimate interests are where appropriate.

Note that we may process your personal data for more than one lawful ground depending on the specific purpose for which we are using your data. Please email keith.mcintire@chp.edu if you need details about the specific legal ground we are relying on to process your personal data where more than one ground has been set out in the table below.

Please note that at the time you contact us, it may be the case that we no longer process, hold or store your personal information/data as data processor, in which case we would advise you of this and the need to contact the data controller.

Disclosure of this information

We may disclose your personal information to third parties:

- If we need to do so to our selected suppliers to enable us to deal with your request. Further information is available upon request at keith.mcintire@chp.edu
- If INFORM or substantially all of our assets are acquired by a third party, in which case personal data held by it about our customers will be one of the transferred assets.
- If we are under a duty to disclose or share your personal data in order to comply with any legal obligation, or in order to enforce or apply our Terms and Conditions and other agreements; or to protect the rights, property, or safety of our clients, customers or others.
- Our site may, from time to time, contain links to and from the websites of our partner networks, clients, affiliates or other external websites. If you follow a link to any of these websites, please note that these websites have their own privacy policies and that we do not accept any responsibility or liability for these privacy policies. Before you submit any personal data to our site, you may want to check the policies of our client, for whom we are collecting the data, and whom for your purposes is the data controller. In the absence of any details being listed on our site, you may contact us at keith.mcintire@chp.edu

Information Use, Legal Basis, Sharing, Disclosure, and Retention

(a) Use and Legal Basis.

Sales and Service Delivery. INFORM uses personal data for developing and issuing sales proposals and for providing its products and services – and justifies this under the legal basis of “Contract”.

Marketing Emails. INFORM uses personal data to update existing clients and prospective B2B client with information about our services. We justify this through a “Legitimate Interests” assessment and offer opt-out functionality for those no longer wishing to hear from us in this way.

We also capture requests for marketing emails through our website sign-up function and justify this through “Legitimate Interests” and, again, offer functionality for those no longer wishing to hear from us in this way.

Reminder / Engagement Emails to Third Party Exhibitors. INFORM uses data provided by event owner clients to inform and remind their exhibitors of key operational information and of our and others’ “official contractor” services – electrics, shell, furniture and flooring – to ensure that ordering deadlines are not missed and that requirements for these services are understood. We justify this through a “Legitimate Interests” assessment.

Engagement Emails and Vital Information to Event Registrants. INFORM captures registration details of event attendees where it has been contracted to do so by third party event owners and justifies this through “Consent”. This may include rudimentary medical data captured for an attendee’s vital interest, such as dietary requirements, allergies or accessibility / inclusivity requirements. Our processes provide full transparency that this data is then shared with the event owner.

Administrative and Legal. INFORM process small amounts of employee and subcontractor data under the legal basis of “Contract” and, if in the Vital Interests of the data subject, or with specific consent, or to comply with Employment or Health and Safety or another Legal requirement will hold special category data such as medical history or driving convictions.

(b) Sharing.

INFORM does not share, sell, rent or trade personal information with any third parties for marketing or promotional purposes. It will only share limited data with suppliers where required operationally and with clients (where the data has been collected on their behalf in the first instance).

It does share small quantities of employee data for administrative and legal purposes.

It also reserves the right to share data with relevant authorities if compelled to do so to comply with legal obligations. We will use third party payment processors for card transactions to pay for goods and services, but these third parties are authorised to use the data only as necessary to provide these services to us and are prohibited from using your personal information for promotional purposes.

(c) Disclosure.

INFORM may disclose personal information under the following circumstances:

- In certain situations, we may disclose personal data in response to lawful requests by public authorities, including but not limited to national security or law enforcement requests. We may also disclose your personal information as required by law, such as to respond to court orders, or similar legal processes, to establish or exercise our legal rights or, defend against legal claims, or if in our judgment in such circumstance’s disclosure is required or appropriate.
- If we believe it is necessary in order to investigate, prevent, or take action regarding illegal activities, suspected fraud, situations involving potential threats to the physical safety of any person, violations of our various terms of use, or as otherwise required by law.

(d) Retention.

We will retain existing customer information for as long as a customer account is active with us or as needed to provide our services – and where required to comply with our legal obligations, resolve disputes, and enforce our agreements. We will retain all prospective customer data until any such time that we receive a request to opt-out.

Details of retention periods for different aspects of your personal data are available upon request from us.

Confidentiality and Security

We use physical, electronic, and procedural safeguards to protect personal information. Our IT arrangements aspire to “Data Protection by Design” and should be able to detect a significant data breach. Where such a breach could result in discrimination, damage to reputation, financial loss, loss of confidentiality or any other significant economic or social disadvantage we will notify the ICO, if we are the Controller, or our client, in the event they

are the Controller. Where a breach is likely to result in a high risk to the rights and freedoms of individual data subjects, we will also notify those concerned directly and at the earliest practical opportunity. We shall then fully investigate a data breach and implement corrective action to prevent recurrence.

By using our services or providing personal information to us, you are consenting to INFORM communicating with you electronically regarding security, privacy, and administrative issues related to your use of our services. We may post a notice on our website if a security breach occurs. In these circumstances, we may also send an email to you at the email address you have provided to us.

Data transmissions over the Internet are not 100% secure. Consequently, we cannot guarantee or warrant the security of any information you transmit to us and you do so at your own risk. Once we receive your transmission, we use reasonable efforts to ensure security on our systems.

Right to Be Informed

We strive to ensure that all those engaging with us are informed of our arrangements for processing personal data through this Privacy Statement which is linked to from our email signatures and website home page.

Right of Access

We will respond to data requests within 1 month and will only charge for requests that are manifestly unfounded or excessive. If we have grounds to refuse a request, we will inform the data subject and make them aware of their right to complain to the ICO or to seek civil action – again within 1 month of receiving the request.

Right to Rectification

For personal data obtained directly from a data subject under the legal basis of consent and obtained indirectly from a data subject under the legal basis of legitimate interest, we will correct any inaccuracies in a data subject's personal data upon receipt of a request. For personal data held under the legal basis of "Contract" or "Vital Interests" or "Legal Obligations" we will endeavour to correct the data upon request but may not be able to do so if changing the data may conflict with our legal obligations or disadvantage us in a future legal action. In cases where we cannot rectify the data for these reasons, we shall inform the data subject and make them aware of their right to complain to the ICO or to seek civil action.

Right to Erasure

For personal data obtained directly from a data subject under the legal basis of consent and obtained indirectly from a data subject under the legal basis of legitimate interest, we will erase a data subject's personal data upon receipt of a request / opt-out notification. For personal data held under the legal basis of "Contract" or "Vital Interests" or "Legal Obligations" we will endeavour to erase data upon request but will not be able to do so if holding the data is necessary to fulfil our legal obligations or may be necessary as evidence in a future legal action involving us. In cases where we cannot erase the data for these reasons, we shall inform the data subject and make them aware of their right to complain to the ICO or to seek civil action.

Right to Restrict Processing

For personal data obtained directly from a data subject under the legal basis of consent and obtained indirectly from a data subject under the legal basis of legitimate interest, we will restrict the processing of a data subject's personal data upon receipt of a request / opt-out notification. For personal data held under the legal basis of "Contract" or "Vital Interests" or "Legal Obligations" we will endeavour to facilitate the requested restriction upon request but will not be able to do so if restricting the processing of the data prevents us from fulfilling our legal obligations or the current processing of the data may be necessary as evidence in a future legal action involving us. In cases where we cannot restrict the processing of the data for these reasons, we shall inform the data subject and make them aware of their right to complain to the ICO or to seek civil action.

Right to Data Portability

For personal data obtained directly from a data subject under the legal basis of consent, we shall provide, upon receiving a request, the data that we hold in a standard, widely accessible format.

Right to Object

For personal data obtained directly from a data subject under the legal basis of consent and obtained indirectly from a data subject under the legal basis of legitimate interest, we will cease to process a data subject's personal data upon receipt of a request / opt-out notification.

Changes to this Privacy Statement

INFORM reserves the right to revise, modify, or update this statement at any time. We will notify you via email about material changes in the way we treat personal data or by placing a prominent notice on this website.

Contacting INFORM

If you have a privacy concern regarding INFORM, or this statement, you may contact us via keith.mcintire@chp.edu or send in writing to;

INFORM
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