

Privacy Notice

Introduction

This notice describes how and why Myrovlytis Trust uses personal information, how we protect your privacy when doing so and your rights and choices regarding this.

Myrovlytis Trust operates via 3 separate entities: Myrovlytis Trust, BHD Foundation and Osteosarcoma Now. This policy applies to all of them.

In the policy where MT websites are discussed it refers to all 3 websites we operate via

<https://myrovlytistrust.org> <https://thebhdfoundation.org> <https://osteosarcomanow.org>

Myrovlytis Trust (MT) ("we") promises to respect the personal information you share with us, or that we receive from other organisations, and to keep it safe. We aim to be clear when we collect your information about what we will do with it and not do anything you wouldn't reasonably expect.

In this policy we use the term personal information to mean any information you give us from which you can be identified. This might include your name, home address, personal email contact details, or your telephone number. Personal information does not include information where your identity has been removed (i.e. anonymous data).

Developing a better understanding of our supporters through their personal information allows us to make better decisions, target our projects more efficiently and, ultimately, helps us move closer towards finding new treatments for the rare conditions we focus on by providing research funds, awareness, information and support.

Our marketing communications include updates around our work, how to access our services and how to support us and get involved. If you would like to receive such communications but do not currently do so, or would like to change the way you hear from us, please email us at contact@myrovlytistrust.org

The processing of personal information is carried out by or on behalf of The Myrovlytis Trust. Myrovlytis Trust is a registered charity in England and Wales (1122073). We are listed on the Information Commissioner's register of data controllers under Registration Number **C1363202**

HOW we collect information about you

We collect personal information in the following ways:

Information you provide to us directly.

You may give us your information to access our services, book on to an event, tell us your story, donate, participate in fundraising activities, register as a volunteer, apply for research funding or otherwise communicate with us.

Information you provide to us indirectly.

Your information may be shared with us by third parties, for example:

- From a family member or a friend who contacts us on your behalf
- Independent event organisers, such as the London Marathon
- Fundraising sites like Just Giving
- If a fundraiser passes on your details to us
- If you are a researcher and your information is shared with us by the principal investigator or institution
- If you apply for a job Myrovlytis Trust via an external recruitment website
- Subcontractors acting on our behalf who provide us with technical, payment or delivery services.

Such third parties will only share your information with us when you have indicated that you wish to support Myrovlytis Trust. When you provide personal information to a third party that is an organisation, you should check their Privacy Policy/Notice in order to fully understand how they will process your data.

Information from other sources

Information available publicly

We may supplement information that we already know about you with information from publicly available sources such as charity websites, annual reviews, corporate websites, public social media accounts, the electoral register and Companies House in order to gain a better understanding of your interests and support of the Myrovlytis Trust and to improve our information provision, governance and fundraising. For more information, please see our section on *'How we use your information - 10. Telling you about our work'*.

Websites, Apps and Social Media

When you use our website, we collect personal information using "cookies" and other tracking methods. Please read our [Cookie Policy](#) to find out more information about this.

As with most websites, "cookies" help us make our site – and the way you use it – better. Cookies mean that a website will remember you. They're small encrypted text files located in browser directories that websites transfer to your computer (or phone or tablet). They make interacting with a website faster and easier – for example by automatically filling your name and address in text fields. Cookies often contain a unique number which can be used to recognise your device when returning to a website previously visited.

In addition, and in accordance with common website practice, we will receive information about the type of device you are using to access our website or apps. The settings on that device may provide us with information about your device, including what type of device it is, what specific device you have, what operating system you are using, what your device settings are, and why a website or app crash has happened. Your device manufacturer or operating system provider will have more details about what information your device makes available to us.

Video conferencing applications like Zoom provide MT with personal information of those attending MT calls. This will include your name and email address, and may include your start time, leave time, chat logs, the call transcript, any files uploaded or shared during the call and whether you gave consent to be recorded.

During a video conferencing call, other attendees may be able to access your name, see you and hear you (including the people or information within your surroundings) unless blocked through host or participant settings. You should be aware that during Zoom recordings a transcript of any private chats will be available to the room owner.

As a Zoom user it is recommended that you familiarise yourself with Zoom's privacy policy (<https://zoom.us/privacy>). This includes how Zoom uses your personal data when hosting a call and your rights and choices around that.

Depending on your settings or the privacy policies/notices for social media and messaging services like Facebook, WhatsApp or Twitter, you might give us permission to access information from those services, for example when you publicly tag us in an event photo.

The MT website, social media accounts, and general correspondence such as the newsletter, may contain links to other websites. When you click on one of those links you are accessing a website that is not owned, operated or controlled by us or any of our affiliates. The operator of such a site may have its own Privacy Notice/Policy, which we encourage you to read carefully. The notice will govern the collection and use of your data on that site.

WHAT personal information we collect about you

Our services provide support to individuals and families affected by Birt Hogg Dube Syndrome and Osteosarcoma and we collect personal data in order to efficiently provide those services. We will only ever collect the information we need – including data that may be useful to help improve our service. The type and quantity of information we collect and how we use it depends on why you are providing it.

If you support us or access our services – for example contact a member of our support team, request an information pack, make a donation, volunteer, register to fundraise, sign up for an event – we will usually collect the following information:

- Your name
- Your contact details (address, email address, telephone number(s) and/or social media identity)
- Information about support, events, and activities in which you have shown an interest
- Your bank or credit card details (if any transaction is involved)
- Information about your activities on our website and about the device you use to access it, for instance your IP address and geographical location.

Where it is appropriate/necessary we may also ask for:

- Information relating to your/your child's health (for example if you are accessing support services, or taking part in/attending an event for health and safety purposes)
- Your date of birth
- Your gender
- Your ethnicity

- Why you have decided to donate to us. We will never make this question mandatory and only want to know the answer if you are comfortable telling us.
- Information as to whether you are a tax payer to enable us to claim Gift Aid (UK only)
- Where you have left us a legacy, any information regarding next of kin which you may have provided to us, for administration purposes

If you apply for research funding, we may ask for:

- Information necessary to process your application, such as your contact details and employment history.
- The employment history of individuals who will be working on the grant.
- Salary information for anyone whose salary will be funded by the grant.

If you volunteer for us or apply for a job with us:

- Information necessary for us to process the application and assess your suitability (which may include things like employment status, previous experience depending on the context, as well as any unspent criminal convictions or pending court cases you may have)

Special Category Data

Certain types of personal information are in a special category under data protection laws, as they are considered to be more sensitive. Examples of this type of sensitive data would be information about health, ethnicity, religious beliefs, or sexuality.

We only collect this type of information about our service users and stakeholders to the extent that there is a clear reason for us to do so, for example asking for health information to ensure we provide the best information and support services, or ethnicity to ensure that our services are accessible and inclusive. We will also collect this type of information if you make it public or volunteer it to us.

Wherever it is practical for us to do so, we will make clear why we are collecting this type of information and what it will be used for.

Children's Data

We will always seek consent from a parent/carer/legal guardian before collecting information about children under the age of 16.

Our fundraising events have specific rules about whether children can participate and we ensure that advertising for those events makes this clear and is age appropriate.

HOW we use your information

1. Fulfilling your requests and supporting you

To respond to or fulfil any requests, complaints or queries you make to us.

If you contact us directly, we will use the information you give to us to answer your question(s), give advice or guidance and to provide you with the services, products or information you have asked for. This may include sharing your details with other Myrovlytis Trust staff to process your enquiry, respond to your query or feedback, or send you relevant information such as fundraising materials (if you have requested them) or information on disease related topics. We will also keep a record of your relationship with us – such as conversations we have with you, feedback you may provide and any marketing materials we send out to you. We use this information to help us understand how we can improve our services, products or information and handle queries more efficiently.

To process any donations you make, claim any relevant Gift Aid, and maintain a record of your past or potential future financial contributions.

This includes keeping a record of any pledges, gift agreements or any other indications that you are planning to donate to Myrovlytis Trust, either now or in the future. We keep a record of any donations we receive for audit (eg. administering our accounts) or legal purposes (eg. we are legally required to keep information related to Gift Aid for six years). We may also need to use your information to prevent fraud.

To provide you with information and support for any services, events, fundraising and campaigning activities or volunteering opportunities you sign up to

You may have completed a form – either online, over the phone or in person with a member our Support Team – to access our Support services. We will send you information relevant to you, by your preferred communication methods (eg. email) which you will have indicated as part of the form completion process.

If you have completed a form to register or enquire about a Fundraising event or activity, or to sign up to one of our campaigns, webinars or video conferences we will send you details about the event, activity or campaign and provide you with support throughout. We may send this information and support to you by post, phone, email, social media, or any other channels for which you have provided your details.

You can email us at contact@myrovlytistrust.org at any time if you would like to update the ways in which you hear from us or if you prefer not to receive this information.

Where appropriate, we will use the information you provide to identify any help we can offer, specific to the activity you have signed up for and to provide necessary information to event organisers. Where this includes information about your health or other sensitive information, we will only use this information if you have given your consent for us to do so.

We may also receive information from event organisers or through third party websites such as JustGiving so that we know you are fundraising for us.

2.Processing funding applications and for grant administration

To monitor the appropriate use of grant funds, including expenditure on individual salaries and consideration of any requests relating to the transfer of items between financial accounts.

3. Administering our research funding

To monitor the appropriate use of MT research funds, including expenditure on individual salaries. If you are or have been an MT funded researcher, we may be in contact for updates on the long-term impact of research funding.

4. Administering the BIRT Registry

Patient privacy and data security are extremely important to everyone involved in BIRT. The Pulse Inframe platform was designed from the ground up to support international regulatory data standards such as GDPR, HIPAA, PHIPA, etc. Patient privacy therefore begins with removing all identifying information, such as name, age, sex, and more from a patient's health information as it's entered into BIRT.

Next, let's discuss researcher and clinician access. Security processes and technologies are integrated into all aspects of the BHD patient registry, so only the right people may access the data they are authorized and entitled to see. This access also includes what patients consent to sharing: no data are shared without a patient's clear consent. A consent form is digitally available and verified by DocuSign.

Finally, there's what patients themselves can access. Patients can access to their own data at any time and can consent to share their data with providers and other relevant parties as they see fit.

The registry's platform is powered by Pulse Inframe.

- Pulse is compliant with both HIPAA (Health Insurance Portability and Accountability Act) and PHIPA (Personal Health Information Protection Act).
- The Registry is also compliant with the General Data Protection Regulation (GDPR) (Regulation (EU) 2016/679).
- Additionally, the Pulse computer program does not interfere with the settings, preferences or commands of a user's computer or device, nor does it change or interfere with data stored on the device. It does not connect to or send messages to other computer systems without the user's authorization or install programs that may be activated by a third party without the user's knowledge.

5. Operating our website

We may use your information to:

- display content to you in a way appropriate to the device you are using (for example if you are viewing content on a mobile device or a computer).
- administer our website and to troubleshoot, perform data analysis, research, generate statistics and surveys related to our technical systems.
- monitor website use to identify visitor location, guard against disruptive use, monitor website traffic and/or personalise information which is presented to you.

6. Safeguarding purposes

We may use personal information for safeguarding purposes, to protect the rights of staff, volunteers, service users and stakeholders.

7. Conducting due diligence and ethical screening

We may use personal information to conduct due diligence and ethical screening.

8. Meeting our legal obligations

We may need to use personal information to meet our legal obligations. For instance, to perform contracts between yourself and us; establish, defend or enforce legal claims; carry out fraud prevention and money laundering checks; meet our obligations to regulators, government and/or law enforcement bodies. Other examples include where a child reports abuse; where someone reports serious self-harm or a serious intention of harming someone else; or other issues relating to our safeguarding practice. We will only share your details in exceptional circumstances or where legally required to do so.

9. Managing our recruitment (including volunteering)

When applying for a role (including voluntary roles) with Myrovlytis Trust via our website, third party online recruitment portal, or through a recruitment agency, the personal data you provide as part of the recruitment process will only be held and processed for the purpose of the selection processes and in connection with any subsequent employment unless otherwise indicated. You will be asked to provide certain information including your name, contact details, employment history and qualifications. This information is mandatory to consider your application, communicate with you about your application and where successful, follow up with references or meet our statutory and internal monitoring and reporting responsibilities. We may also view social media profiles of applicants, such as LinkedIn, to the extent that it is relevant to your application. Unsuccessful applicant data will be held confidentially within the recruitment system for a period of 12 months from the date of application (or date of interview if one took place) before it is deleted.

10. Telling you about our work

Sending you direct marketing communications (eg. information about our events)

We will contact you to let you know about support services that may be useful to you and your family, ways to give or raise money for us, ways to campaign or volunteer for us and general updates on our work. We make it easy for you to tell us how you want us to communicate with you in a way(s) that suits you. All our online forms contain clear communication preference questions and anything we post or email to you will include information on how you can change these or ask us to stop contacting you at any time. Please see paragraph c) below for further details.

1. a) By post

Where it is appropriate and relevant and you have provided us with a postal address, we will occasionally write to you. We do this as we consider it is a legitimate interest to promote our charitable cause and communicate with you about ways you can support us and we can support you.

2. b) By email and phone

Where it is appropriate and relevant and you have provided us with an email address and/or telephone number and told us that you are happy to hear from us in this way, we will occasionally call or email you. We may contact you without explicit consent to inform you of support services that we feel may be relevant and of interest to you. We

do this as we consider it is a legitimate interest to communicate with you about ways we can support you. We will not email you or call you to promote fundraising activities without your explicit consent.

3. c) Managing how you hear from us

You can tell us to stop contacting you, or change the way in which we do so, by emailing us at contact@myrovlytistrust.org. All such requests will be updated on our database within 21 days. We will keep a record of any requests to stop receiving communications from us to ensure that we do not communicate with you in the future, unless you tell us you want to hear from us again.

If you decide to tell us that you no longer wish to receive marketing communication from us, we may still need to contact you for administrative purposes. For example, where we are processing a donation you've made and any related Gift Aid, in order to thank you for a donation or participation in an event, or to keep in touch with you about any volunteering or fundraising activities you are doing for us.

4. d) Consent

We recognise that consent to contact you doesn't last forever and that circumstances change, therefore you will only hear from us for 5 years from the last time you told us how you want to hear from us. If we have not heard from you for a while then before the end of the 5 year period we will contact you again to request your refreshed communication preferences.

11. Making sure we speak to you in way that is relevant to you and understanding our supporters better

We try to ensure that our communications are as effective as possible so that we make the best use of the money we spend on them. This means communicating with people in different ways, appropriate to them.

On occasion, we will use information about how you have interacted with us previously, for example the record of your previous donations to us and the type of activity you have been involved with, to tailor our communications with you about future activities. We may also use information about how you use our website (eg. Google Analytics) or how you interact with our emails (eg. by monitoring open rates) to make them more effective and improve engagement with our service users and stakeholders.

In certain circumstances we may use information from publicly available sources such as online registries, websites, media or social media, or personal introductions in order to understand more about your interests and preferences so that we can better tailor our communications – telling you about the things you are likely to be interested in, or letting you know of ways to fundraise with us which is relevant to you. We may do this by looking up such information as your career information, peer networks, listed directorships, demographic information, interests, or other information.

External data sources include publicly available information such as Companies House, Charity Commission and other charity registers, Electoral Roll, reputable newspaper articles, publications, company websites and biographies on professional networking sites as well as geographic and demographic information based on your postcode. This allows us to segment our database and gives us a better understanding of our supporters. Importantly, it enables us to raise more funds, sooner, and more cost-effectively, than we otherwise would. We will

analyse data from our database so that we can understand our supporters and tailor our services. This information may include levels of engagement and giving history.

If you would prefer we didn't use your information in the ways listed above, then you have the right to tell us to stop by getting in touch with us – email contact@myrovlytistrust.org

12.Using images or videos you share with us

If you share photos about fundraising or campaigning activities you have done for us, or send them to us directly, we may want to use this to help us promote our events and activities in the future. If we do, we would contact you to obtain your consent.

13.Using comments you have made about us

If we think a comment you have made about our services, events or information might be helpful in promoting and explaining the relevant services to other users, either in printed or online/e- communications, we will contact you to ask for permission to use that comment. We would never publicly attribute a comment to an individual without obtaining prior consent.

14.Using images or videos we take of you

We regularly take photographs at MT events which we use to promote MT via our website, on social media, in our publications and possibly in the press. We ask those attending events who do not wish to be photographed or would not wish their photograph(s) to be used, to let us know as soon as possible.

Our video conference sessions are often recorded and attendees will always be informed that this is happening. Any stills or videos from these recordings featuring participant information will only be shared with participants' prior explicit consent. Attendees will be informed if/how we plan to share the content in advance of the recording. However, in the event sharing certain content with a relevant third party is needed to protect a person's interests (i.e. for safeguarding purposes) the participant may not be informed.

We abide by a policy of best practice when hosting Zoom calls and take reasonable measures to protect the privacy of those attending before, during and after the call. If you would like more information about how we do this, please contact contact@myrovlytistrust.org

15.Undertaking our campaigning activity

We maintain a record of information related to MPs and other holders of public office, to enable us to undertake our campaigning activity to improve the patient experience and to help reach our charitable goal. This will include keeping a record of contact details such as address, telephone number and email address as well as publicly available voting records and committee and group memberships.

16.Sharing your story

MT regularly invites families and supporters to tell their stories to illustrate our work. These stories may be then used:

- On MT's websites and promoted on social media.
- In the public media including printed press and magazines, online media and broadcast.
- In our annual report.
- In our electronic newsletters.
- As case studies when applying for funding.

The content of all stories is approved in writing by the individual concerned prior to publication.

While some personal information is invariably included in such stories, we do not publish addresses. In the case of young people under the age of 16 we do not publish surnames.

If MT is contacted by the media for further details of an individual once a press release has been issued, such details are only revealed with the consent of the person concerned.

17. Better understanding the wider context of the effects of Birt Hogg Dube Syndrome and Osteosarcoma

We may use personal information to inform our understanding of patterns and trends in the diagnosis, treatment and care of people affected by the conditions we support.

How We Keep Your Data Safe and Who Has Access

We ensure that there are appropriate technical controls in place to protect personal details. We restrict access to information that we hold about you and/or your family to ensure that it is only accessible by appropriately trained staff and volunteers who need to know the relevant information.

We do not hold video conference recordings without prior consent or a valid legal basis, and will only retain chat logs, transcripts or any other information uploaded during a video conference call to meet the legal obligations set out at the end of this document. All data we process in this way is covered by GDPR.

Sharing your information with other organisations

We do not sell or share personal details to third parties for the purposes of marketing. However, we may disclose your information to third parties in connection with the other purposes set out in this notice.

These third parties may include:

- business partners, suppliers and sub-contractors who may process information on our behalf (eg. a mailing house)
- joint funders of research, host institutions and external members of our committees
- researchers who are utilising our Research Hub and working with its members
- analytics and search engine providers (for more information see our [Cookie Policy](#))
- IT service providers
- hotels, and activity organisations
- hospitals, health and social care professionals and grant giving trusts
- regulatory bodies
- challenge event organisers
- other organisations with whom we run an event in partnership.

On occasions, we use external companies to process your details (name and address) on our behalf, for example to assist us with large bulk mailings. We do comprehensive checks on these companies before we work with them and put a confidentiality agreement in place.

Any personal information sent to external companies is always transferred in a secure manner and password protected. Password information is then provided separately. Such companies comply with all relevant laws applicable to the collection, storage, use and/or processing of personal data. They also maintain the confidentiality of all details processed on MT's behalf and have systems adequate to ensure their security. Any details provided are only used for the purpose for which they are supplied (eg. to fulfil the mailing) and upon completion of the work all details are deleted and nothing is stored (in any format).

If you take part in a challenge event (eg. London Marathon) for MT we will provide the event organiser with your name and any other details they require to enter you for the event.

Where we are under a legal or regulatory duty to do so, we may disclose your details to the police, regulatory bodies, or legal advisors, and/or, where we consider this necessary, to protect the rights, property or safety of Myrovlytis Trust, its staff, service users or others.

Some of our suppliers run their operations outside the European Economic Area (EEA) – this may include a country which may not be subject to the same data protection laws as companies based in the UK. In these circumstances, we will take steps to make sure they provide an adequate level of protection in accordance with UK data protection law, and appropriate safeguards are in place.

Please see below a list of companies who may process data on our behalf – please note this list is subject to change and not exhaustive –

- JustGiving
- Eventbrite
- Stripe
- Mailchimp
- Pulse Inframe
- CAF
- Paypal
- Facebook
- Xero
- Lloyds Bank

We will only ever share your details in other circumstances if we have your explicit and informed consent.

Keeping Your Information Up To Date

We really appreciate it if you let us know when your contact details change. We will never use publicly available sources to keep your records up to date – you have a right to choose what information you provide to us and you don't have to update your details if you don't want to.

Legal Basis for Processing

Data protection laws mean that each use we make of personal information must have a "legal basis". The relevant legal bases are set out in the UK General Data Protection Regulation and in current UK Data Protection (section 8) legislation.

Specific Consent

Consent is where we ask you if we can use your information in a certain way, and you agree to this (for example when we send you direct marketing material via post, phone, text or e-mail). Where we use your information for a purpose based on consent, you have the right to withdraw consent for any future use of your information for this purpose at any time.

Legal Obligation

We have a basis to use personal information where we need to do so to comply with one of our legal or regulatory obligations. For example, in some cases we may need to share your information with various regulators such as the Charity Commission, Fundraising Regulator, Information Commissioner, or to use information we collect about you for due diligence or ethical screening purposes.

Performance of a contract / take steps at your request to prepare for entry into a contract

We have a basis to use personal information where we are entering into a contract with you or performing our obligations under that contract. Examples of this would be if you are applying to work/volunteer with us or being funded to undertake research.

Vital Interests

We have a basis to use personal information where it is necessary for us to protect life or health. For instance, if there were to be an emergency impacting individuals at one of our events, or a safeguarding issue which required us to contact people unexpectedly or share information for safety reasons.

Legitimate Interest

Further to the legal reasons described above, another lawful reason that allows us to process personal information under GDPR is called 'legitimate interest'. This means that the reason that we are processing information is because there is a legitimate interest for MT to do so to help us to achieve our vision of providing information and support to patients, raising awareness among clinicians and the public and strategically funding research, (provided that what the information is used for is fair and does not unduly impact your rights).

We consider our legitimate interest to include all day-to-day activities MT carries out with personal information. Some examples not mentioned under the other bases above where we are relying on legitimate interest are:

- analysis and profiling of our supporters using personal information we already hold.
- sending information regarding charitable activities that MT feels may be relevant to you based on your past engagement or personal circumstances.

- use of personal information when we are monitoring the use of our website or apps for technical purposes.
- use of personal information to administer, review and keep an internal record of the people we work with, including supporters, volunteers, and researchers.

We only rely on legitimate interest where we have considered any potential impact on you (positive and negative), how intrusive it is from a privacy perspective and that your rights under data protection laws do not override our interests in using your information in this way.

When we use sensitive personal information, we require an additional legal basis to do so under data protection laws. We will either do so on the basis of your explicit consent or another route available to us in law for using this type of information (for example if you have made the information manifestly public, we need to process it for employment, social security or social protection law purposes, your vital interests, or, in some cases, if it is in the public interest for us to do so).

Your Rights

Under UK data protection law (General Data Protection Regulation (GDPR)), you have rights over the personal information we hold about you. These rights are summarised below: -

Right to access personal information

You have a right to request access to the personal data that we hold about you. You also have the right to request a copy of the information we hold about you, and we will provide you with this unless legal exceptions apply.

Right to have inaccurate personal information corrected.

You have the right to have inaccurate or incomplete information we hold about you corrected. If you believe the personal information we hold about you is inaccurate or incomplete, please provide us with details and we will investigate and, where applicable, correct any inaccuracies.

Right to restrict use of personal information

You have a right to ask us to restrict the processing of some or all of your personal information in the following situations: if some information we hold on you isn't right; we're not lawfully allowed to use it; you need us to retain your information in order for you to establish, exercise or defend a legal claim; or you believe your privacy rights outweigh our legitimate interest to use your information for a particular purpose and you have objected to us doing so.

Right to erasure of personal information

You may ask us to delete some or all your personal information and in certain cases, and subject to certain exceptions, you have the right for this to be done.

Right for personal information to be portable.

If we are processing your personal information (1) based on your consent, or to enter or carry out a contract with you, and (2) the processing is being done by automated means, you may ask us to provide it to you or another service provider in a machine-readable format.

Right to object to the use of personal information.

If we are processing personal information based on our legitimate interest, or for scientific/historical research or statistics, you have a right to object to our use of your information.

If we are processing personal information for direct marketing purposes, and you wish to object, we will stop processing your information for these purposes as soon as reasonably possible.

Exercising Your Rights

If you wish to exercise any of the above rights, please write to us at The Myrovlytis Trust, 26 Cadogan Square, London, SW1 OJP enclosing proof of your identity and a description of the information you would like to see. We do not accept these requests by email to ensure that we only provide personal data to the correct person.

We will endeavour to respond fully to all requests within one month of receipt of your request, however if we are unable to do so we will contact you with reasons for the delay. If there are any discrepancies in the information we provide to you, please let us know and we will correct them.

Please note that exceptions apply to a number of these rights, and not all rights will be applicable in all circumstances. For further details we recommend you refer to the guidance published by the UK's [Information Commissioner's Officer](http://www.ico.org.uk/for-the-public/personal-information/) (ICO) (www.ico.org.uk/for-the-public/personal-information/).

If you have any questions please e-mail us at contact@myrovlytistrust.org

Complaints

If you are unhappy with any aspect of how we use personal information, we'd like to hear from you. We appreciate the opportunity this feedback gives us to learn and improve. You can find out more and read the Compliments and Complaints Policy on our website <https://myrovlytistrust.org/compliments-and-complaints-policy/>

You also have the right to make a complaint to the Information Commissioner's Office (www.ico.org.uk), the UK data protection regulator.

Myrovlytis Trust is registered with the Fundraising Regulator to demonstrate our commitment to meeting fundraising standards. If you have any complaints regarding charitable fundraising please visit the Fundraising Regulator's website (www.fundraisingregulator.org.uk/complaints/make-complaint) or call 0300 999 3407.

Changes to this Privacy Notice

We may update this Privacy Notice from time to time to reflect changes in how we use your information. You may therefore wish to check this notice each time you provide the Myrovlytis Trust with your information. Where appropriate, we will provide you with notice of any significant changes to how we use your information.

Contact Us

If you have any questions or comments about this privacy notice and how we use your information you can contact us at:

The Myrovlytis Trust, 26 Cadogan Square, London, SW1 OJP

Email: contact@myrovlytistrust.org

Telephone: 020 8050 2091

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