



FEWS PRIVACY NOTICE

Your personal data – what is it?

“Personal data” is any information about a living individual which allows them to be identified from that data (for example a name, photographs, videos, email address, or address). Identification can be directly using the data itself or by combining it with other information which helps to identify a living individual.

The processing of personal data is governed by European legislation relating to personal data which applies in Belgium, the country in which the FEWS organisation is registered), being the EU regulation 2016/679 of the European parliament and of the council on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/45/EC (General Data Protection Regulation).

Who are we?

This Privacy Notice is provided to you by the European Federation of Williams Syndrome (“FEWS”) which is the data controller for your personal data.

FEWS will process some or all of the following personal data where necessary to perform its tasks:

- Names, titles, and aliases;
- Contact details such as telephone numbers, addresses, and email addresses;
- We may process information such as gender, age, education, family composition, and dependants;
- We may process financial identifiers such as bank account numbers, payment card numbers, payment/transaction identifiers, policy numbers, and claim numbers, such as for the purpose of paying grant funding or prize monies.
- Express consent has been provided for all photographs stored / used by the FEWS.
- IP addresses and website visit histories, logs of visitors, and logs of accidents, injuries and insurance claims.

FEWS does not hold or process sensitive data, as defined by <https://www.dataprotectionauthority.be/sensitive-data>.

How we use personal data

We need all the categories of personal data in the list above primarily to allow us to engage in a manner that is relevant to our objectives, your interest in our organisation, whilst at the same time complying with legal obligations.

Do we need your consent to process your personal data?

In limited circumstances, we may approach you for your written consent to allow us to process certain personal data. If we do so, we will provide you with full details of the personal data that we would like and the reason we need it, so that you can carefully consider whether you wish to consent.



FEWS will comply with data protection law. This says that the personal data we hold about you must be:

- Used lawfully, fairly and in a transparent way.
- Collected only for valid purposes that we have clearly explained to you and not used in any way that is incompatible with those purposes.
- Relevant to the purposes we have told you about and limited only to those purposes.
- Accurate and kept up to date.
- Kept only as long as necessary for the purposes we have told you about.
- Kept and destroyed securely including ensuring that appropriate technical and security measures are in place to protect personal data from loss, misuse, unauthorised access and disclosure.

We use your personal data for some or all of the following purposes:

- To manage your relationship with us and to keep you informed of relevant activities and information;
- To contact you by post, email, telephone or using social media (e.g. Facebook, Twitter);
- To maintain our own accounts and records;
- To seek your views, opinions or comments;
- To notify you of changes to our activities, events and officers;
- To send you communications which you have requested and that may be of interest to you. These may include information about events, FEWS resources, research information;
- To process relevant financial transactions including grants, fundraising, gift-aid and legacies.

What is the legal basis for processing your personal data?

FEWS is a small charity registered in Belgium initiated as the official association of national organisations across Europe which are actively involved in supporting people with the rare genetic condition, Williams Syndrome (WS). FEWS exists to pursue the following objectives:

- To spread awareness of Williams Syndrome at the European level, by amplifying the awareness-raising activities of individual national associations
- To ensure effective co-ordination of and collaboration between national and regional WS organisations in Europe, avoiding the unnecessary duplication of resources
- To help direct individuals with WS, as well as their families and carers, to appropriate providers of support
- To co-ordinate international research efforts by connecting relevant research institutes and professionals with WS organisations
- The sharing and translation of relevant publications and guidance materials into the languages of member associations
- To organise and participate in international congresses
- To promote and manage contact between WS organisations and research institutes outside of Europe

Sharing your personal data

This section provides information about the third parties with whom FEWS may share your personal data. These third parties have an obligation to put in place appropriate security measures and will be responsible to you directly for the manner in which they process and protect your personal data. It is likely that we will need to share your data with some, or all, of the following (but only where necessary):



- Our officers and delegates (those appointed to FEWS as representatives of the national WS associations that are members of FEWS).
- Our agents, suppliers and contractors. For example, we may ask a commercial provider to publish or distribute magazines on our behalf, or to maintain our database software.
- On occasion, researchers, if we have received consent from you.
- Upon your request, when you have asked for support in a medical / educational / social care issue and we need to share your personal details to obtain the help you need. This will only occur with your express consent.

How long do we keep your personal data?

We will keep some records permanently if we are legally required to do so. We may keep some other records for an extended period of time. For example, it is currently best practice to keep financial records for a minimum period of 10 years to support tax audits or provide tax information. We may have legal obligations to retain some data in connection with our statutory obligations. FEWS is permitted to retain data in order to defend or pursue claims. In some cases, the law imposes a time limit for such claims. We will retain some personal data for this purpose as long as we believe it is necessary to be able to defend or pursue a claim. In general, we will endeavour to keep data only for as long as we need it. This means that we will delete it when it is no longer needed.

Your rights and your personal data

You have the following rights with respect to your personal data:

When exercising any of the rights listed below, in order to process your request, we may need to verify your identity for your security. In such cases we will need you to respond with proof of your identity before you can exercise these rights.

- **The right to access personal data we hold on you**
At any point you can contact us to request the personal data we hold on you as well as why we have that personal data, who has access to the personal data and where we obtained the personal data from. Once we have received your request we will respond within one month.
- **The right to correct and update the personal data we hold on you**
If the data we hold on you is out of date, incomplete or incorrect, you can inform us, and your data will be updated.
- **The right to have your personal data erased**
If you feel that we should no longer be using your personal data or that we are unlawfully using your personal data, you can request that we erase the personal data we hold. When we receive your request, we will confirm whether the personal data has been deleted within 30 days or the reason why it cannot be deleted (for example because we need it for to comply with a legal obligation).
- **The right to object to processing of your personal data or to restrict it to certain purposes only**
You have the right to request that we stop processing your personal data or ask us to restrict processing. Upon receiving the request, we will contact you and let you know if we are able to comply or if we have a legal obligation to continue to process your data.
- **The right to data portability**
You have the right to request that we transfer some of your data to another controller. We will comply with your request, where it is feasible to do so, within one month of receiving your request.
- **The right to withdraw your consent to the processing at any time for any processing of data to which consent was obtained**



You can withdraw your consent easily by email or by post (see Contact Details below).

- **The right to lodge a complaint with the Belgian Data Protection Authority**

You can contact the Data Protection Authority on <https://www.dataprotectionauthority.be/>.

Transfer of Data Abroad

Any personal data transferred to countries or territories outside the European Economic Area (“EEA”) will only be placed on systems complying with measures giving equivalent protection of personal rights either through international agreements or contracts approved by the European Union. [Our website is also accessible from overseas so on occasion some personal data (for example consented photographs) may be accessed from overseas].

Further processing

If we wish to use your personal data for a new purpose, not covered by this Privacy Notice, then we will provide you with a new notice explaining this new use prior to commencing the processing and setting out the relevant purposes and processing conditions. Where and whenever necessary, we will seek your prior consent to the new processing.

Changes to this notice

We keep this Privacy Notice under regular review and we will place any updates on this web page https://eurowilliams.org/privacy_policy. This Notice was last updated in October 2019.

Contact Details

Please contact us if you have any questions about this Privacy Notice or the personal data we hold about you or to exercise all relevant rights, queries or complaints at:

Email: paul.pyck@eurowilliams.org