

PRIVACY POLICY

KETOTIC HYPOGLYCEMIA INTERNATIONAL

This Privacy Policy explains how the Ketotic Hypoglycemia International association ("KHI", "We", "Us") processes your personal data.

1 DATA CONTROLLER

The entity responsible for the processing of your personal information is

Ketotic Hypoglycemia International
CVR: 41171944
Kærgårdsvej 21 8660 Skanderborg
c/o Danielle Drachmann
Email: drachmandanielle@gmail.com
Phone: 50691008

2 DESCRIPTION OF THE PROCESSING

Purposes

2.1 List of members

We process personal data about you if you chose to become a member of our association. We process your personal data, including name and email address, which we receive from you, to administrate our association, including inviting our members to our general meetings and invite you to participate in surveys to gain a greater knowledge regarding idiopathic ketotic hypoglycemia (IKH).

If you are an active member of our association pursuant to our articles of association we may process your area of work and educational background or that either you or one of your relatives suffer from IKH, but it will not be possible for us to determine who suffers from the disease, unless you provide us with this information pursuant to section 2.4.

The legal basis for processing your personal data is GDPR art. 6.1.b, because these personal data are necessary for the administration of your membership.

The personal data is shared with data processors that provide IT-services to us.

The personal data is processed until you decide to end your membership or until it is no longer necessary for the purpose it was collected for.

2.2 Surveys

When you are a member of KHI, we will sometimes invite you to participate in various surveys. If you decide to participate in the surveys, we process your personal data in the form of your answers to obtain a greater knowledge and do research on IKH.

The specific personal data related to the survey that we process, is described in each survey, but will often include you and your child's age and your observations/feelings about your child's disease. Further, we will often process sensitive data about your child, including symptoms and of course the diagnosis itself.

The legal basis for processing your personal data is consent pursuant to the GDPR art. 6.1.a and 9.2.a.

The personal data is shared with data processors that provide IT-services to us. Further, KHI prepare reports on the results from the surveys, that will be shared with the IKH research groups.

The personal data is processed until you withdraw your consent or until it is no longer necessary for the purpose it was collected for.

2.3 Newsletter

We process personal data about you when you sign up for our newsletter. We process your personal data to be able to send you the newsletter.

We process personal data about you, including name and email address, which we receive these from you.

The legal basis for processing your personal data is GDPR art. 6.1.f because we have a legitimate interest in providing our members with newsletters containing information regarding our association.

The personal data is shared with data processors that provide IT-services to us.

The personal data is processed until you withdraw your consent or until it is no longer necessary for the purpose it was collected for.

2.4 Patient videos

KHI offers to make patient videos to help you process that you or one of your relatives suffers from IKH. These videos are published by KHI on its social media pages to raise awareness regarding IKH and our association. In order for us to create and publish these videos we process the personal data that you provide us with regarding you or your child.

We process personal data about you and your child, including name, email address, age, pictures, and video recordings. Further, we process sensitive data i.e. health data, including diagnosis and symptoms. We may also process other personal data, should you provide this.

We receive these data directly from you.

The legal basis for processing your personal data is consent pursuant to the GDPR art. 6.1.a and 9.2.a.

The personal data is shared with data processors that provide IT-services to us. Furthermore, you and your child's data are published on social media with unlimited public access.

The personal data is processed until you withdraw your consent or until the videos are deleted from the social media.

3 TRANSFERS TO COUNTRIES OUTSIDE THE EU/EEA

We will to some extent transfer your personal data to Google and other social media platforms, located in the USA. Furthermore, the data may be transferred to Google's or the social medias' subsidiaries or sub-processors in the USA or other third countries outside the EU/EEA. The USA and other third countries usually do not ensure a level of protection essentially equivalent to that ensured within the EU/EEA. To this concern, you must be aware that the third countries may not provide for effective legal remedies to exercise your rights and may allow unjustifiable access to personal data by public authorities. The legal basis for these transfers are the standard contractual clauses prepared by the European Commission pursuant to GDPR art. 46.2.c.

4 YOUR RIGHTS

You have the following rights:

- You have the right to request access to, rectification or erasure of your personal data.
- You also have the right to have the processing of your personal data restricted.
- If processing of your personal information is based on your consent, you have the right to withdraw your consent at any time. Your withdrawal will not affect the lawfulness of the processing carried out before you withdrew your consent. You may withdraw your consent and exercise your rights as described below.
- You have the right to receive your personal information in a structured, commonly used and machine-readable format (data portability).
- You may always lodge a complaint with a data protection supervisory authority, e.g. The Danish Data Protection Agency.

Furthermore, you have the right to object to processing of your personal data as follows.

- If processing of your personal data is based on article 6(1)(f), see above regarding legal basis, you have the right to object, on grounds relating to your particular situation, at any time to the processing of your personal data.
- Where your personal data are processed for direct marketing purposes, you have the right to object at any time to the processing of personal data about you for such marketing.

You can take steps to exercise your rights by sending an email på drachmandanielle@gmail.com.

There may be conditions or limitations on these rights. It is therefore not certain for example you have the right of data portability in the specific case - this depends on the specific circumstances of the processing activity.