



Privacy Statement

The website “Bohring-Opitz Syndrome - A worldwide exchange of information and awareness” (Bohring-Opitz.org) is a private (funded) initiative. On 25 May 2018, the European Union’s General Data Protection Regulation (GDPR) rules on privacy and the processing of personal data went into effect. Even though we are not an official organization or company, we believe it is important that the privacy of the volunteers, activists and visitors of our website is guaranteed and Bohring-Opitz.org adheres to this new Privacy Regulation. Personal data is therefore handled with the utmost care and is maintained confidential secure.

Contact details

Bohring-Opitz.org is responsible for the processing of personal data as set out in this privacy statement located at

H.J. Koenenstraat 13

2012BA HAARLEM

The Netherlands

Phone +312353131096

www.bohring-opitz.org

Sünne van Gemert-Godbersen and Sheri Bermejo are responsible for the data protection of Bohring-Opitz.org. They can be reached via sunne@bohring-opitz.org and sheri@bohring-opitz.org.

E-mail

If you, as a visitor to our website, provide your email address to Bohring-Opitz.org, you will be kept informed of new Blog posts of Bohring-Opitz.org by e-mail. You can opt out of e-mails at any time via the unsubscribe link in the e-mail you send.

Personal data that we process

Bohring-Opitz.org processes your personal data by using our services and / or by providing this information to us.

Data is never provided by Bohring-Opitz.org to third parties for commercial purposes.

Below you will find an overview of the personal data we process, among other things:

- First and last name
- E-mail address

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- Other personal data that you actively provide, for example by creating a profile on this website, in correspondence and by telephone
- Date of birth
- Address data
- Phone number
- Location data
- Images
- Stories

We will never publish personally identifiable information about you or your child on the website of Bohring-Opitz.org.

Special and / or sensitive personal data that we process

Bohring-Opitz.org processes the following special and / or sensitive personal data, which you actively provide, about:

- your child's health
- details of your child, younger than 16 years

Our website and / or service does not intend to collect data about website visitors who are younger than 16 years, unless they have permission from parents or guardians. However, we cannot check if a visitor is older than 16. We encourage parents to be involved in the online activities of their children, in order to prevent data about children being collected without parental consent. If you are convinced that we have collected personal information about a minor without this permission, please contact us at sunne@bohring-opitz.org and we will delete this information.

Automated decision-making

Bohring-Opitz.org does not make decisions based on automated processing on matters that can have (significant) consequences for individuals. These are decisions made by computer programs or systems, without involving a person (for example, a Bohring-Opitz Syndrome employee).

Bohring-Opitz.org uses the following computer programs, systems or applications:

- Our website is made with wordpress.com. With wordpress.com we can create, maintain and manage the website bohring-opitz.org in-house. This website strives to make current knowledge about Bohring-Opitz Syndrome accessible to everyone. It also aims to connect families and professionals caring for a child affected with Bohring-Opitz Syndrome. Wordpress is part of Automattic. For more

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information on Automattic's privacy policy visit <https://automattic.com/privacy/> and <https://en.support.wordpress.com/automattic-gdpr/>

- We use online questionnaires to share knowledge about health and development of children with Bohring-Opitz Syndrome. Data published from these questionnaires are anonymous. We use Polldaddy to collect this information. Polldaddy is also part of Automattic or Wordpress. For more information about Polldaddy's privacy policy visit <https://polldaddy.com/privacy/>
- We use the interactive maps of GoogleMaps to give families the opportunity to interact with other families in their neighborhood. Contact details are only exchanged with prior consultation and with the approval of the person concerned.
- In order to offer parents and caregivers of a child with Bohring-Opitz Syndrome the opportunity to come into contact with each other and exchange experiences and support, we created the Bohring-Opitz Syndrome Support Group (<https://www.facebook.com/groups/okketje>). This Support Group is a closed group on Facebook. For more information about privacy settings on Facebook, click here: <https://www.facebook.com/help/325807937506242/>
- Social media: In order to optimally disseminate and share knowledge about Bohring-Opitz Syndrome and publications about it, the website bohring-opitz.org has social media accounts and links to pages such as:
 - Facebook page (<https://www.facebook.com/childrenwithbos/>),
 - Twitter (<https://twitter.com/childrenwithbos>),
 - LinkedIn (<https://www.linkedin.com/in/childrenwithbos>),
 - Pinterest (<https://pinterest.com/childrenwithbos/>)
 - Google (Google maps, Google translate, YouTube, Google plus) (<https://policies.google.com/technologies/product-privacy>) and
 - Vimeo (<https://vimeo.com/bohringopitzsyndrome>)

On the Bohring-Opitz Syndrome site you will find a number of links to other websites. We bear no responsibility with regard to the handling by these parties with your data. Read the privacy statement, if any, of the site you are visiting.

Length of time personal data is stored

Bohring-Opitz.org does not store your personal data longer than it is necessary to achieve the purposes for which your data is collected. We use a retention period of 10 years for personal data.

Sharing personal data with third parties

Bohring-Opitz.org does not sell your information to third parties.



Cookies

The Bohring-Opitz Syndrome website made with Wordpress.com uses cookies. A cookie is a small text file that is stored in the browser of your computer, tablet or smartphone when you first visit this website. Bohring-Opitz.org uses cookies with a purely technical functionality. These ensure that the website works properly and that, for example, your preferred settings are remembered. These cookies are also used to make the website work well and to optimize it.

On your first visit to our website we informed you about these cookies and we asked you for permission to store them on your computer device.

What can you do if you do not want (certain) cookies?

You can indicate via the settings of your browser (for example Internet Explorer, Safari, Firefox, Mozilla or Chrome) whether and, if so, which cookies you accept. It varies per browser where these settings are located. Through the 'help' function of your browser you can find out the exact location for the adjustment setting. Please note that if you refuse (certain) cookies, you may not be able to make full use of the functionalities of our website!

Cookies are also placed on this website by third parties. These are social media companies, for example. Please refer to the Cookie Policy of the relevant social media companies and wordpress.com (<https://en.support.wordpress.com/cookies/>).

View, modify or delete data

As an EU citizen you have the right to view, correct or delete your personal data. You also have the right to withdraw your consent to data processing or to object to the processing of your personal data by Bohring-Opitz.org and you have the right to data portability as an EU citizen. This means that you can submit a request to us to send the personal information we have regarding you or another organization mentioned by you in a computer file.

You can send a request for access, correction, deletion, data transfer of your personal data or send a request to cancel your consent or objection to the processing of your personal data to sunne@bohring-opitz.org.

To ensure that the request for access has been made by you, we ask you to send a copy of your ID with the request. Please black out your passport photo, MRZ (machine readable zone, the strip with numbers at the bottom of the passport), passport number and Citizen Service Number (BSN) when sending us a copy. This is to protect your privacy. We will respond as quickly as possible, approximately within four weeks from the day you submit your request.

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Bohring-Opitz.org also wants to point out that you have the opportunity to file a complaint with the national supervisory authority, the Dutch Data Protection Authority.

How we protect personal data

Bohring-Opitz.org takes the protection of your data seriously and takes appropriate measures to prevent misuse, loss, unauthorized access, unwanted disclosure and unauthorized modification. If you feel that your data is not properly secured or there are indications of abuse, please contact us at sunne@bohring-opitz.org.

Amendment

Bohring-Opitz.org reserves the right to make changes to this privacy statement. Therefore, check this privacy statement regularly for the most current Bohring-Opitz.org privacy policy.