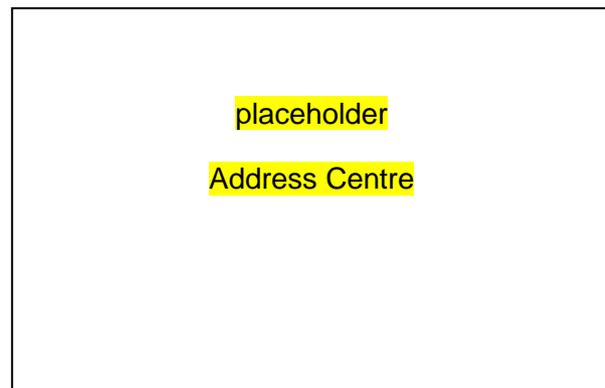


## Information on data protection - Supplement to patient information



*[Salutation, e.g.*

*Dear Patient,*

*Dear Patient/Proband,*

*etc.] ,*

You participate in the following research project:

"International Register of Clinical and Laboratory Chemical Parameters for Primary Immunodeficiencies ("ESID Registry")

The EU General Data Protection Regulation (EU GDPR) applies since 25 May 2018. This also results in partially changed requirements for already ongoing research projects that involve the processing of personal data.

You have agreed to participate in the above research project. With your consent, you have also consented to the collection and processing of your personal data, your health data and medical findings in particular. This consent still applies.

With this data protection supplement we would like to inform you about changes in data protection law as far as the research project in which you participate is concerned.

## **Your rights regarding data protection**

### **Right of access**

You have the right to request information about your personal data processed within the scope of this research project (Art. 15, EU-GDPR) and to receive a free copy of this data.

### **Right to rectification of data**

You have the right to request that your personal data be corrected, if it is incomplete or incorrect (Art. 16, EU-GDPR).

### **Right to restriction of data processing**

You have the right to demand a restriction of the processing of your personal data (Art. 18, EU-GDPR).

### **Right to object**

You have the right to object to the processing of your personal data (Art. 21, paragraph 6, EU-GDPR).

### **Right of revocation (data protection right of revocation)**

You have the possibility to revoke your consent to the processing of your personal data at any time without stating reasons (Art. 7, paragraph 3, EU-GDPR). This does not affect the legality of the processing of your personal data until revoked.

### **Right to erasure**

You have the right to obtain the erasure of personal data (Art. 17, EU-GDPR).

### **Right to lodge a complaint**

You have the right to lodge a complaint if you are of the opinion that the processing of your personal data violates your data protection rights (Art. 77, EU-GDPR).

a. with the supervisory authority responsible for the University Hospital Freiburg:

<u>Office address:</u> Landesbeauftragter für den Datenschutz und die Informationsfreiheit Königstrasse 10 a 70173 Stuttgart	<u>Postal address:</u> Landesbeauftragter für den Datenschutz und die Informationsfreiheit Postfach 10 29 32 70025 Stuttgart
Tel.: 0711/61 55 41 – 0 Fax: 0711/61 55 41 – 15 E-Mail: <a href="mailto:poststelle@lfdi.bwl.de">poststelle@lfdi.bwl.de</a> Internet: <a href="https://www.baden-wuerttemberg.datenschutz.de">https://www.baden-wuerttemberg.datenschutz.de</a>	

b. with the supervisory authority of your treatment centre:

(placeholder contact details  
supervisory authority, documenting centre)

**Questions about the research project or data protection:**

If you have any further questions regarding the research project, data protection or any of your rights, or if you wish to claim any of your rights, please contact your physician or your documenting treatment centre. You can also contact the head of the research project or the central contact point of the ESID registry. You can also contact the supervisory authorities responsible for you or your centre. The contact information can be obtained via the website of the Federal Commissioner for Data Protection in Germany, the respective contact in your country, or at any time via the Central Contact Point, your doctor or treatment centre:

[https://www.bfdi.bund.de/DE/Infothek/Anschriften\\_Links/addresses\\_links-node.html](https://www.bfdi.bund.de/DE/Infothek/Anschriften_Links/addresses_links-node.html)

**Contact information:**

The controller of the data thus responsible for data processing in this research project is the "European Society for Immunodeficiencies, ESID", represented by the ESID Executive Committee, which is represented by the Chairperson of the ESID Registry Working Party (who is also a member of the Executive Committee), The ESID Executive Committee is determined by election within the ESID members.

Information on ESID, the ESID Registry, the Chair of the Registry Working Group and contact details are regularly made publicly available on the ESID website ([www.esid.org](http://www.esid.org)) and can also be obtained at any time from your treating physician, documenting treatment centre or the ESID Registry Central Contact Point.

- *The chairman of the Registry Working Group for the period until October 2022 is:*

**Mikko Seppänen**  
Chief Physician  
MD, PhD, Specialist in Internal Medicine and Infectious Diseases, Adjunct Professor  
**HUS Helsinki University Hospital, Children and Adolescents, Rare Disease Center**  
Majakka, P.O.Box 281, 00029 HUS | Stenbäckinkatu 11, Helsinki  
E-Mail: [mikko.seppanen@hus.fi](mailto:mikko.seppanen@hus.fi)  
Tel.: +358 50 4279606

- *Central contact point of the ESID Registry*

ESID-Register  
c/o UNIVERSITÄTSKLINIKUM FREIBURG  
Institut für Immundefizienz im Zentrum für Translationale Zellforschung  
Breisacher Straße 115  
79106 Freiburg  
Germany  
Tel.: 0761/270-36961  
Fax: 0761/270-36960  
E-Mail: [esid-registry@uniklinik-freiburg.de](mailto:esid-registry@uniklinik-freiburg.de)  
Homepage: <https://esid.org/Working-Parties/Registry-Working-Party/ESID-Registry>

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- *Data Protection Officer of the University Hospital Freiburg:*

Universitätsklinikum Freiburg Datenschutzbeauftragter Agnesenstraße 6 – 8 79106 Freiburg E-Mail: <a href="mailto:datenschutz@uniklinik-freiburg.de">datenschutz@uniklinik-freiburg.de</a>
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- *Data protection officer of your documenting centre:*

<b>(Placeholder local Data protection official at documenting centre)</b>
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