

# Nursing Forum for EB Care

supported by  ebClinet  
Linking clinical expertise in EB.

## Data Protection Information

### Network/forum for nurses and care professionals working with patients with Epidermolysis Bullosa

Dear Colleague,

The EB Nurses Forum is set up as an email distribution list. If you have a question or information for the community, please address it to the email address [nurses@eb-clinet.org](mailto:nurses@eb-clinet.org)

All emails sent to this address will be automatically redirected to the distribution list of the EB Nurses Forum. If you would like to answer a question or respond to information that has reached you via this email address, please make sure to cc the address [nurses@eb-clinet.org](mailto:nurses@eb-clinet.org) so that everyone in the community receives your answer.

If you would like to join the distribution list, please send the signed consent form to EB-CLINET ([office@eb-clinet.org](mailto:office@eb-clinet.org)).

#### **Purpose:**

This distribution list was created to provide a platform for the exchange of questions, knowledge and experiences between professionals working in the field of EB care. This platform should be easily accessible. Therefore the email address [nurses@eb-clinet.org](mailto:nurses@eb-clinet.org) has been created. Everyone joining the forum will be added to the distribution list associated with this email and will automatically receive all emails directed to this email address.

#### **Persons responsible / Contact:**

The forum was initiated by José Duipmans (Advanced Nurse Practitioner, University Medical Center Groningen; [j.c.duipmans@umcg.nl](mailto:j.c.duipmans@umcg.nl)) and Sharon Cassidy (Clinical Nurse Specialist (EB), DEBRA New Zealand; [sharon.cassidy@debra.org.nz](mailto:sharon.cassidy@debra.org.nz)) and is supported by EB-CLINET (EB House Austria, University Hospital Salzburg, [office@eb-clinet.org](mailto:office@eb-clinet.org)).

#### **Data:**

For the administration of the EB Nurses Forum distribution list your personal data (name, email address, job title, institution, country) will be stored in a database. Your data will be only accessible for the persons responsible (see above) and to the provider of the EB Nurses Forum email address. All persons having access to your data are obliged to confidentiality. We have an agreement in accordance with the European GDPR with this provider. The data will only be used for the purpose of administration of the distribution list of the EB Nurses Forum email address.

#### **Questions & Answers Documents:**

To make the knowledge and opinions which have been shared in the forum available for all members, also for those members who enter the forum later, we collect the questions which have been posted in the forum and the answers to those questions in specific Q&A documents, clustered by topics. These documents are available on the EB-CLINET website and are protected by a password, which is communicated to the members of the forum. Members are not allowed to share this password with people outside of the forum.

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If consented, we add the names of the participant who posted the question or answer beneath it, to enable other participants to get in contact in case of further questions or to further discuss the issue.

## **Your rights:**

Your consent for giving your personal data to be part of the EB Nurses Forum and for adding your email address to the distribution list is voluntary. It can be withdrawn at any time. In case of withdrawal your data will be deleted and no longer used from this moment on.

# Nursing Forum for EB Care



## Consent Form for Nursing Professionals Working in the Field of EB Care

Please enter your data here:

Name:

Email address:

Job title:

Institution:

Country:

I give consent for the storage of my personal data (name, email address, job title, institution, country) and for sharing some of the data (name, job title, institution, country) with the participants of the forum	Yes <input type="checkbox"/>	No <input type="checkbox"/>
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I give consent for the publication of my name in the password protected Q&A documents (if one of my posts is covered).	Yes <input type="checkbox"/>	No <input type="checkbox"/>
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I confirm that I give consent for the utilization of my data as described in the information sheet. It is guaranteed that your data will be treated according to the regulations of the Austrian Data Protection Act. I understand that my participation in this initiative is voluntary. If you do not wish to be included in the distribution list anymore, you can withdraw at any time without giving any reason by emailing EB-CLINET ([office@eb-clinet.org](mailto:office@eb-clinet.org)).

\_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Signature of the professional*