



PSYCHOSOCIAL

Support for parents caring for a child living with epidermolysis bullosa (EB)

**This is how life feels
to people with EB.**



WHAT IS EPIDERMOLYSIS BULLOSA?

EB is a group of rare genetic disorders characterised by fragility of the skin and mucous membranes and mechanically induced blistering. EB comprises four main types - EB simplex (EBS), junctional EB (JEB), dystrophic EB (DEB), and Kindler EB (KEB), with more than 30 subtypes. EB is clinically heterogeneous including a broad spectrum of severity.



Valentina Compagnoni Pretko, living with recessive dystrophic EB, aged 1, Brazil (photo credit: Cristiane Martins)



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Artwork by Felipe Pliego Pontin, living with recessive dystrophic EB, aged 7, Brazil



What is psychosocial support?

Psychosocial support means helping to support psychological, social, emotional, and spiritual well-being. This is formed during a person's lifetime and is influenced by environmental factors as well as factors that are unique to each individual.

Who is this booklet for?

This booklet is for parents of a child with any of the following types of EB:

- ▶ EB simplex (EBS)
- ▶ dystrophic EB (DEB)
- ▶ junctional EB (JEB)
- ▶ Kindler EB (KEB)
- ▶ EB acquisita (EBA) - autoimmune, not genetic*

*There was no evidence found in this population group for the CPG. However, it is assumed that they would require the same support.

What is this booklet about?

This booklet provides information on psychosocial support for parents caring for a child with EB.

Topics covered in this booklet include:

- ▶ the parent-child relationship
- ▶ wound care and pain management
- ▶ life stages and transitions
- ▶ impact on family life
- ▶ care for the caregiver
- ▶ communication

Where does the information in this booklet come from?

The information and recommendations in this booklet are derived directly from the “Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based guidelines”. The guidelines were written in 2018 by a group of EB healthcare professionals, individuals living with EB, and family members. The information and recommendations in the guidelines come from a variety of sources including clinical research and expert opinion.

There are three different types of recommendations in this booklet:



STRONG RECOMMENDATION
based on good-quality
research evidence



RECOMMENDATION
based on research
evidence



RECOMMENDATION
based on clinical
experience



This icon signposts to recommendations that overlap with those from other EB clinical practice guidelines (CPGs). These are referenced to on page 33.



“ For every child we do not know exactly what the future will bring. We need a balanced image of what will happen in real life: there are also special and amazing moments that you will share with your child not just pain and suffering. ”

Adriana Taguchi, mother to Mariana born with junctional EB with pyloric atresia, (3 September – 11 November 2009), Brazil

As parents it can be very concerning if it appears your newborn child has EB. The expectation and hope for a healthy child has changed to that of a child who will have to deal with EB throughout his or her life. Grieving for everything that your child may or, in particular, may not experience is entirely normal. Adapting to this situation is a long-term process.

As parents, you are faced with the challenge of raising your child as normally as possible. The consequences of having a child with EB can create obstacles. For example, it is not always easy for you to physically touch, hold, or comfort your child. Concern for hurting him or her during wound care can also be very difficult, especially when your child does not understand the reason for the pain. These obstacles can make achieving a secure bond between you and your child more difficult. However, this bond is essential for your child to be able to feel safe and confident, and is something they will also transfer to their relationships with other people.

You have the challenge of stimulating your child to become as independent as possible, whilst balancing their physical needs and limitations. An appropriate way in which you can accompany your child on this journey is by facing the challenges together, taking time to enjoy achievements and the special times.



“ I remember as a child when we changed my dressings and they got stuck in the night. We had to soak them off in the bath. We made the bathroom a good place to be; we always used music, my mother used to sing, we had a brightly-coloured table with everything we needed. When I was in the bath they rolled in the TV so I could watch cartoons, I was allowed to eat my dinner in the tub if I wanted to. ”

Ida Steinlein, living with recessive dystrophic EB inversa, aged 31, Norway

One of the biggest challenges in EB is wound care, which can be stressful for you and your child. How you interact with your child and how you deal with wound care is very important. This mostly daily care (characterised by lancing blisters, applying creams, and changing dressings) can greatly influence your daily routine (see the skin and wound care CPG).

Developing a fixed routine is important and carrying out wound care in a dedicated space is advised. Wound care is often painful so it is important to acknowledge your child’s feelings and use techniques to make the experience more bearable. Distractions (including taking part in pleasurable activities), such as deep breathing exercises (including using bubbles or pinwheels for little children), listening to music, humour, eating, watching TV or films, telling stories, singing songs together, and playing with toys help to cope with the pain.

Talking to your child’s healthcare provider/EB team about pain relief and tips to make wound care easier is important. It can help you feel more confident in managing your child’s wound care. Your child will then learn from this process as they get older so they can become confident in managing their EB, trust others to look after their skin, and manage their pain in the best way possible.



“ The intense daily physical care was a big part of our relationship with our son and his identity. When he was 8 and very unwell, we decided outside carers might give us the space to just be parents so he could develop as a child with fragile skin only a part of who he was and not the focus of our relationship with him. We had to fight for government funding, and from then we did no more bandage changing until he was nearly 20 years old, with a strong sense of self. It was very hard to give up our hands-on role, he was very upset by the change at first, but slowly and steadily his health improved, the extent of his damaged skin reduced, and he started to grow again. We train and manage the support staff so we have confidence in them. Not being hands-on was the best thing we did for him. It’s made a huge difference to his life and ours, we are certain this has helped him to survive and thrive. ”

Martin Hanley, father of Humphrey living with recessive dystrophic EB, aged 36, New Zealand



Top tips for wound care and pain management

- ▶ have a fixed routine
- ▶ use a dedicated space
- ▶ use distractions and take part in pleasurable activities
- ▶ talk to your child’s EB team/healthcare provider about pain relief and wound care tips.

Your EB team/healthcare provider can:

- ▶ explain why pain management is important
- ▶ discuss any doubts you may have in providing your child with pain medication
- ▶ offer effective approaches to manage chronic and acute pain (see the pain management CPG)
- ▶ make a personal pain plan, especially if there are serious wounds. This should include yours and your child’s opinions where possible.

It is important to involve other care providers in wound care at an early stage so that you and your child can have the opportunity to function independently of each other. This also helps your child to learn to trust others to take care of their skin, something that will be important as he or she grows older. It is also important that your child learns to actively participate in his or her care and express his or her own opinions about this. Young children can be taught to participate in wound care by letting them unwrap some of the bandages. As they grow older, they can gain more control by having a voice in decisions that have to be made. Gradually, they can participate more and more becoming as independent as possible.



Recommendation

Involve other healthcare providers in your child’s wound care to provide relief and support for you as primary caregivers and parents. Access to this support is different in each country. Contact your EB team/healthcare provider and/or your national DEBRA group for more information.



“ As a mum I want to wrap him up and keep him safe but I know I can't do that. I want him to be a kid, as normal as possible. I tell kindergarten not to stop him if he wants to do something. I don't want to tell him 'no, don't do that' because he'll have wounds. He has to find out himself, to find his way in life, to know his boundaries; he will learn his own consequences. ”

**Kari Anne Bø, living with EB simplex Oigna, aged 36
mother of Adrian with EB simplex Oigna, aged 3, Norway**

Working with the nursery and schools that your child will attend will allow them to be prepared to support a child with EB. Once your child is nearer school age, you should research local schools and the added support they are able to provide. This support might be chaperoning your child to and from classes so they do not get knocked in corridors by other students or helping your child during classes with activities, such as writing.

It may also be possible to gain vital equipment, such as a laptop, to give your child further independence. Arranging a meeting with the head of the school, your child's teacher, and support assistant in advance is beneficial. Providing leaflets, giving talks, or showing a film about EB can also help. Your EB team/healthcare provider and/or your national DEBRA group may be able to assist you with this. Starting school will be less stressful for you and your child if the school is well informed about EB and what it means for your child, so staff can provide support as needed.

This preparation remains necessary for every transition to a new school or place of work. School is a place where children can learn in many areas, which is why it is important to encourage your child to attend school where possible, despite the challenges that they experience as a result of EB.



“ I said to my son there’s no excuse for not having done homework. He is clever, he can do his homework but he realises that EB can be an excuse “oh I had this pain” or “this happened” when really he could have done his homework just fine! ”

Vlasta Zmazek, mother to Matija born with recessive dystrophic EB (1983 – 2018), Croatia

You can also stimulate your child’s development by encouraging him or her to participate in social activities. Every transition to a new social situation may require you to support your child in this. It is important that a child with EB is allowed to experience what a typical child would. More forward planning and caution may need to be taken to minimise any potential skin damage, such as using extra dressings, elbow/knee pads, or special cushioned insoles. It is beneficial to include the organisers of a particular activity in the planning so they are aware of your child’s EB and can make any adaptations to aid their participation if necessary or possible. Explaining what EB is and the physical boundaries associated with it can help your child to have access to social activities.

“ When kids don’t have limits and they are not pushed to do better, you are transmitting to them that they are not capable, that it doesn’t matter if they don’t do something because they won’t achieve it anyway. ”

Florencia Pérez, Psychologist, DEBRA Chile



Osmijeh ne košta ništa,
a djeluje čudesno.

“ Very often as a parent I find he is much more capable than I even thought that he would be. Once when I was out he walked to his friend’s house, I couldn’t believe he had travelled all the way on his own! When he rang me expecting a lift home I said ‘well done but no’, he has to wait for me to be ready to get him or to find his own way home. It helps him to learn to be responsible, to plan and to problem solve, so he can learn how to live his life as an adult. It’s a balance between being supportive, encouraging them to experiment, having boundaries and discipline and pushing your child to do the best they can. ”

Vlasta Zmazek, mother to Matija born with recessive dystrophic EB (1983 – 2018), Croatia

The adolescent phase is another stage in life that requires preparation given the many new responsibilities that are expected of young adults, such as learning to drive, moving out, paying bills, and going to university or work. The question here is to what extent your child can achieve his or her independence as best as possible. You can encourage your child to achieve his or her goals within manageable limits, to develop his or her interests and opinions, and to discover what he or she is good at.

Expert opinion

- ▶ Although healthcare providers are able to advise with general “dos and don’ts”, it is only through allowing your child to experience new things that you are able to learn what their limitations are, as each person with EB is affected differently. This allows your child to shape their own identity and sense of independence, a sense of having value, meaning, and a role.
- ▶ Prepare for every transition by considering which challenges you and your child may face. Communicate clearly what EB means for your child and you, and what considerations and expectations you have.



Iasmin Santos Martin, living with EB simplex, aged 7, Brazil (photo credit: Suelen Szymanski)



EB may not only lead to a potentially reduced quality of life for your child but the whole family. This impact is noticeable socially, emotionally, and physically. This may include difficulties in maintaining friendships or having negative feelings, such as powerlessness and guilt, because you cannot protect your child from discomfort. A job may also come under pressure because an employer's expectations cannot be properly combined with the care for your family. Given the many stressful circumstances that you can face, receiving psychosocial support early on is desirable. This can come in different forms, from speaking to friends to seeking professional support. Receiving this support before experiencing any serious symptoms is preferable. Symptoms may include sleep changes, loss of energy, negative feelings/thoughts of self-harm or suicide, and loss of interest in daily activities.

Siblings of a child with EB can often face challenges of their own. For example, they may unintentionally receive less time and attention from their parents, be expected to be more self-reliant at a younger age, help out more at home, and keep an eye out for their sibling at school. It is very important that you are aware of what is going on in all of your children's lives and how they are feeling in order to avoid any built-up resentment or ill feeling towards their sibling with EB. Having regular set times spent together as a family is really important. It is also important for parents to spend one-to-one time with the unaffected sibling too.

Recommendations

- ▶ Get psychosocial support early on to prevent family breakdown.
- ▶ Have regular set times to spend together as a family.

Your EB team/healthcare provider can:

- ▶ explain what psychosocial service(s) they can offer you.





Geovanna Vale da Silva, living with recessive dystrophic EB, aged 4, Brazil
(photo credit: SOS EB Kids, by Marcela Melo)

Raising a child with EB can be a complex task for parents. Not only will you have to deal with the regular challenges that being a parent brings, you also have to cope with a lot of other roles. Besides being a parent, you have to become an expert in EB with techniques for wound care. You have to organise yourselves to keep on top of all the paperwork, such as hospital appointments. Sometimes you will have to plan every day in advance in order to get your child to school or to leisure activities. Maybe one of you will have to stop working in order to have enough time for all of this. Besides this, you are still a man or a woman, a husband or a wife, a son or a daughter, a brother or a sister, a friend, an individual with your own interests and leisure activities. There are many roles in your lives and keeping up with every one of them is a complex task to balance.

Understandably, most of your time and attention is given to your child affected by EB, which has an impact on you as a couple. Your relationship is put to the test and you may have much less time for each other. However, this is an important issue. You are the people closest to your child and take on all of the responsibility of caring for him or her. When you feel supported and thrive, your child will benefit. When the burden becomes too heavy and everything becomes unbearable for you, the care for your child will be affected. Practical support for wound care and respite care can help relieve the burden. It is advisable to request this support prior to strain being put on the relationship; having regular set times spent together as a couple is really important. It is also very important that partners, friends, family, and providers are aware of this and try to support you. They can do this by asking about how things are going, by doing some of the practical tasks or paper work, or by trying to help organise all appointments that need to be attended.

As parents, you are faced with the challenge of continuing to take good care of yourselves while also providing your child with the best possible care.

Sometimes you have to be convinced of the importance of taking care of yourselves. You sometimes want to put your own needs or interests on hold putting all of your effort into taking care of your child. Nevertheless, to keep doing this you need to take time for yourselves, whether to recuperate and recharge your energy, or to just remind yourselves of who you are as individuals, or why you became a couple. These moments need to be created and planned otherwise life will just pass you by. Self-care may consist of doing something as simple as a hobby once a week, going on a date-night with your partner, or a weekend off without the kids once a year. Self-care is different for everyone, but it is needed to hold on to the continuous and complex care that is required for a child with EB.

Self-care can also consist of seeking professional help, such as a psychologist, if you are going through a particularly hard time. It can allow you to take the time to deal with your feelings and emotions; speaking to somebody who is not emotionally attached to your situation in confidence and without being judged. As the saying goes “It’s ok not to be ok” all of the time! Sometimes parents of a child with EB find it helpful to contact other parents in the same position; they experience a lot of support and understanding via peer-to-peer contact. Your EB team/healthcare provider and/or your national DEBRA group can facilitate this.

Recommendations

- ▶ Have regular set times to spend together as a couple and by yourself.
- ▶ Taking care of yourself is taking care of your child. Use resources that are provided and ask for more if needed.



“ Sometimes kids don’t want to go to school because maybe someone has said something. Explaining to others about EB can help. This demystifies it, otherwise classmates are wondering what is going on, why is she wearing that, why are they doing that, why can’t this person join in, what is ok for me to invite them to do? ”

Ida Steinlein, living with recessive dystrophic EB inversa, aged 31, Norway

In the early stages, right after a diagnosis of EB is made, you are given a lot of information. Most of this information concerns wound care, medical advice or statistics, occasionally issues about health insurance and finances, and where to go for further help. This information is given to you to aid your understanding of EB, how to most appropriately care for your child, and what you can expect life to be like. In a short period of time you become experts in EB and especially what it may entail for your child.

After this, it is expected that you will be the ones to inform other people who will be involved in your child’s day-to-day life about EB: family, day care, school, other physicians, pharmacists, health organisations, and friends. EB is a rare disease and not many people know about it or know how to deal with it. They are not aware of the impact that it can have on daily life and, as a consequence, they sometimes lack understanding, empathy, or support. Having to constantly be the one who has to explain EB to others can sometimes feel like a burden. However, keeping an open line of communication is an important factor in providing the best care for your child. If you find this particularly difficult, your national DEBRA group can help.



Communication with your child and their sibling(s) about EB:

Most information about EB is given to you during the neonatal period. When a child grows up, his or her understanding of the world, and therefore him or herself, becomes more complex. At some point throughout his or her life they will ask questions about their condition. This typically occurs around ages 5-7 when children learn about differences between people. Having a visible physical condition is a difference that becomes more apparent with age. This growing awareness is often paired with difficult questions about their future, such as social stigma (being looked at or treated differently based on their appearance), exploring social situations and relationships, and sometimes premature death.

For most parents, it is not easy to be confronted with those types of questions. It is difficult to face the difficult emotions that their child is experiencing and to give a realistic answer to all those questions. However, it is important that a child gets the right information. In becoming an adult, a child has to know about their own condition and learn to deal with it the best way they can. By giving information on an age-appropriate level, your child can slowly gain awareness of their EB. Professional support, child booklets, or educative games can also help the process.

“ The fears that parents have can sometimes transmit to their child and be limiting to their development. Parents need to teach their child that they can trust in the world, that it is a safe and secure place, not completely risky and terrible. Children need opportunity to develop a sense of confidence, so they learn to trust in themselves and discover that they are able to do things. If parents focus solely on what their child cannot do, then children believe that they are not able; they grow up with the impression that they won't be able to do things and therefore do not try. ”

Kate Martin, Psychosocial Panel Chair & Consultant Clinical Psychologist, adults and families - Solihull Hospital, Birmingham, United Kingdom

The same process should be considered for siblings of a child with EB. They also become more aware of EB, the implications for their family, themselves, and for their sibling as they grow older. They grow up with a brother or sister who gets more attention and time focussed on their care, and for whom there are more worries. Sometimes it is really difficult for them as they feel underestimated in their understanding. It is important to explain EB to siblings, giving them space to talk about and acknowledge their grief, in terms of the impact EB has had on them as well as their sibling with EB.



“ It is important to be in a partnership with providers; we are both experts in EB and we work together. Nobody has all of the answers but we try to figure problems out together. ”

Judith Kristin Asche, living with junctional EB non-Herlitz, aged 57, Norway

Communication as parents:

The relationship you have with your child can sometimes be under stress. The care for a child with EB can conflict with personal dreams, career ambitions, or future plans. Maintaining open and honest communication between you is essential as different perspectives or expectations are natural. Maybe a new balance as a couple needs to be found to prevent you from growing apart. Making time for these conversations and time as a couple is vital. Getting psychosocial support can be helpful during difficult times.

Communication with healthcare providers:

People with a chronic disease will have a lifelong relationship with their medical team. It is not always easy but good communication between both parties is extremely important in order to provide good care for your child. As parents, it is important that you feel listened to, understood, and supported by your child's EB team/healthcare provider. It is important that there is a sense of confidence and trust in order to ask difficult questions or talk about personal things. Only when there is open communication, will you feel that you are fully supported in the care for your child.

When difficult choices need to be made, such as surgery, or when difficult news has to be broken, it is important that this can be done in a safe and open way. As parents, you have the right to know everything about your child's condition and even to ask for a second opinion if you believe that another EB team/healthcare provider may be able to give you different or further answers.

You can also speak to your child's EB team/healthcare provider if you have doubts or want answers or advice about an issue. Sometimes there are no answers and the feeling of powerlessness is overwhelming. This is often equally as difficult for the healthcare provider as they sometimes see that it is their responsibility to provide families with all of the answers. It is important that you as parents and healthcare provider build a good working relationship in order to understand each other and, more vitally, provide the best care possible for your child. It is often the case that parents who attend a clinic with their child come with a list of questions or concerns that they want to address with the EB team/healthcare provider. When seeing a general physician, it is recommended that you request an extended appointment to allow enough time to go through everything you want to efficiently. You can also request to speak to other individuals within the multidisciplinary team and inform them if you do not feel supported or understood.

Tell us what you think

Have your say in the future patient versions of clinical practice guidelines (CPGs) for epidermolysis bullosa (EB)

The purposes of this survey are to:

- ▶ assess the quality of the information, presentation, and delivery of the patient versions
- ▶ help us to develop a standard for all patient versions now and in the future.

The data collected will help us to improve the information provided and experience of the user in all future CPG patient versions. The data may be used to report the development steps taken to improve their quality; this may be done through conference presentations, posters, abstracts, or studies.

We want to make sure that all patient information provided meets the needs of everyone living with EB.

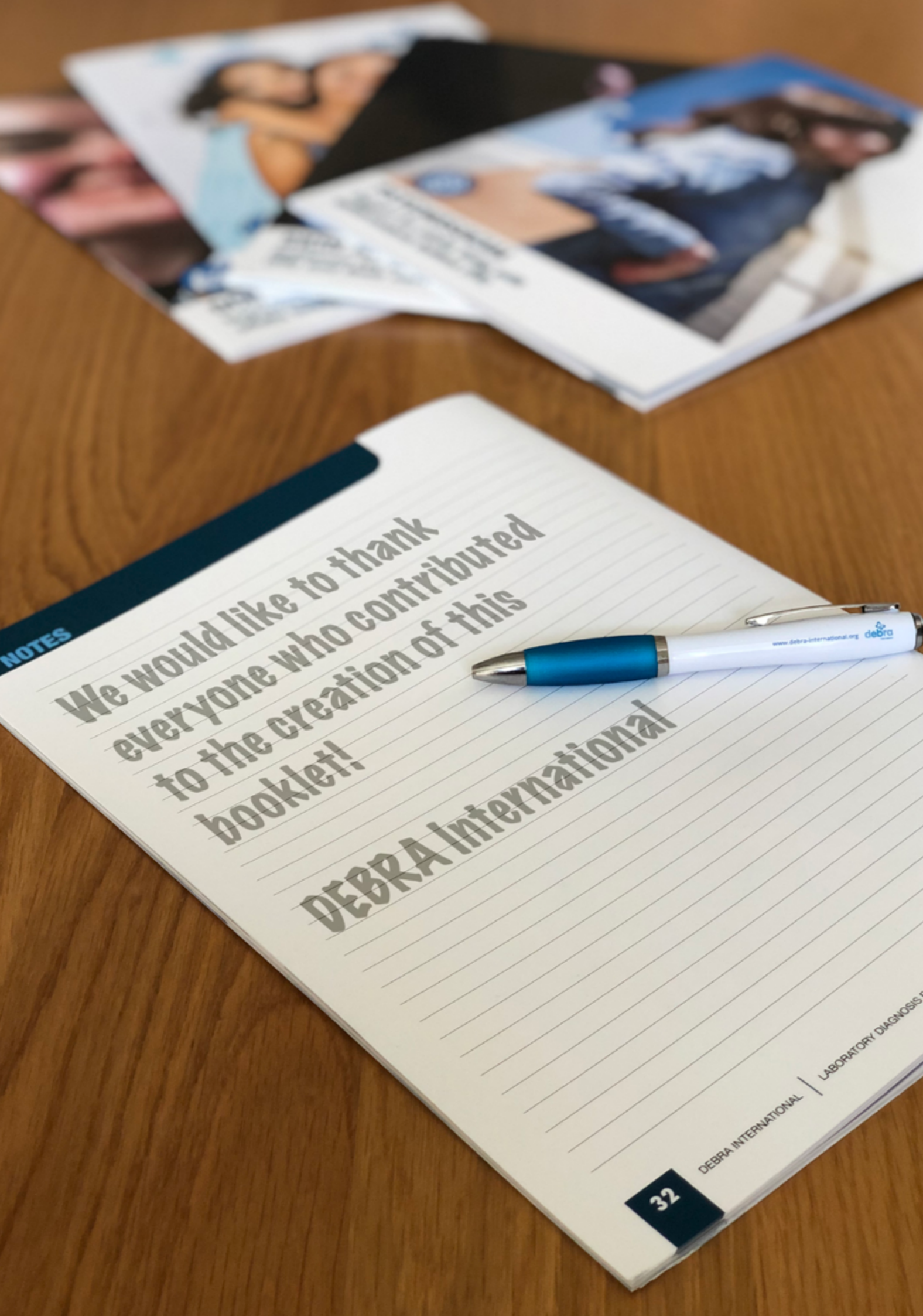
Help us create new CPGs and patient versions

All responses to the above survey are confidential unless you decide to join the DEBRA International CPG network. Please consider joining the network if you are interested in becoming involved in the development of CPGs and patient versions in the future. To join the network, please complete question 1 on page 7. If you do not complete this question, we will not receive any of your personal details and you will remain anonymous. Joining the CPG network is entirely voluntary and you may choose to opt out at any time by contacting DEBRA International.

If you have any questions when completing this survey or about joining the CPG network, please contact the DEBRA International CPG Coordinator, Kattya Mayre-Chilton by email at: kattya.mayre-chilton@debra-international.org

TELL US WHAT YOU THINK!

Answer the survey to help us improve the patient versions of the CPGs:
www.surveymhero.com/c/PatientVersionsSurvey





Júlia da Costa Landim, living with EB, aged 6, Brazil (photo credit: Rodrigo Landim)

Disclaimer

The information contained in this booklet does not indicate an exclusive course of action or serve as a standard of medical care. Variations, taking individual circumstances into account, may be appropriate. The authors of this booklet have made considerable effort to ensure that the information contained within accurately reflects the content of the guidelines on which it is based. The authors, DEBRA Norway, and DEBRA International accept no responsibility for any inaccuracies, information perceived as misleading, or the success of any recommendations, advice, or suggestions detailed in this booklet. The information provided on the following pages is subject to change without notice. For the most up-to-date information on available clinical practice guidelines, booklets, and contact information, please visit: www.debra-international.org

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Development source

Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based guidelines
This CPG was approved by DEBRA International and funded by DEBRA Norway.

To access the following CPGs and patient version booklets, please visit: www.debra-international.org



Psychosocial booklets

- ▶ Psychosocial support for adults living with epidermolysis bullosa (EB)
- ▶ Psychosocial support from your EB team/healthcare providers



Other CPG topics referred to in this booklet



- ▶ Pain care for patients with epidermolysis bullosa: Best care practice guidelines
- ▶ International Consensus Best Practice Guidelines for Skin and Wound Care in Epidermolysis Bullosa

Other CPG topics

- ▶ Clinical Practice Guidelines for Epidermolysis Bullosa Laboratory Diagnosis
- ▶ Foot care in Epidermolysis bullosa: Evidence-based Guideline
- ▶ Management of Cutaneous Squamous Cell Carcinoma in Patients with Epidermolysis Bullosa: Best Clinical Practice Guidelines
- ▶ Occupational therapy for epidermolysis bullosa: clinical practice guidelines
- ▶ Oral Health Care for Patients with Epidermolysis Bullosa - Best Clinical Practice Guidelines

Other languages

We are happy to consider requests for this booklet to be provided in other languages. Please send all enquiries to: office@debra-international.org

How was the Psychosocial guideline produced?

- ▶ The CPG development group consisted of EB experts: psychologists, paediatric dermatologists, nurses, a dietitian, a methodologist, and patient representatives.
- ▶ All panel members completed written conflict of interest and code of conduct declarations.
- ▶ During guideline development, the group met twice in face-to-face meetings to discuss the clinical questions and methodology; review the evidence (publications in the field of EB psychosocial research); formulate recommendations; and agree on the guideline's structure and wording.
- ▶ CPGs are based on a critical, extensive, and exhaustive review of the most relevant publications in the field of EB psychosocial research together with the personal experiences of the panel members.
- ▶ To identify publications, 12 electronic search engines were accessed, including Medline (PubMed MeSH), Embase Emtree PsychInfo, CINHALL, Scopus, and the main search engine for the National Institute for Health and Care Excellence (NICE). Searches were performed using the terms "EB and Psychosocial", "EB and psychologist" and "EB and social" in four different languages with the search period ending December 2018.
- ▶ A total of 601 articles were identified. Finally, 36 papers were appraised, each by two panel members, according to the Critical Appraisal Skills Programme (CASP) and Scottish Intercollegiate Guidelines Network (SIGN) quality rating.

Panel group

- ▶ K Martin - CPG Chair (United Kingdom)
Consultant Clinical Psychologist, adults and families - Solihull Hospital
- ▶ S Geuens - CPG Co-chair; CPG patient version Lead (Belgium)
Clinical Psychologist, adults and paediatrics - Universital Hospitals Leuven
- ▶ J K Asche - CPG Member (Norway)
Person living with EB - DEBRA Norge
- ▶ R Bodan - CPG Member (United States)
Person living with EB - California State University
- ▶ F Browne - CPG Member (Ireland)
Dermatologist - Our Lady's Children's Hospital Crumlin
- ▶ A Downe - CPG Member (United Kingdom)
EB Clinical Nurse Specialist - Guy's and St Thomas' Hospitals NHS Foundation Trust
- ▶ N García García - CPG Member (Spain)
Clinical Psychologist - DEBRA Spain
- ▶ G Jaega - CPG Member (United Kingdom)
Person living with EB - Psychology graduate and person living with EBS, Liverpool
- ▶ B Kennedy - CPG Member (Ireland)
Senior Clinical Psychologist, paediatrics - Our Lady's Children's Hospital Crumlin
- ▶ P J Mauritz - CPG Member; CPG patient version Co-lead (Netherlands)
Child Psychologist - The University Medical Center Groningen
- ▶ F Pérez - CPG Member (Chile)
Clinical Psychologist - DEBRA Chile
- ▶ K Soon - CPG Member (United Kingdom)
Senior Clinical Psychologist, paediatrics
- ▶ V Zmazek - CPG Member (Croatia)
Mother of a person born with EB - DEBRA Croatia
- ▶ K Mayre-Chilton - Project Manager/CPG Member (United Kingdom)
Specialist Adult Research Dietitian - Guy's and St Thomas' Hospitals NHS Foundation Trust

External review group

- ▶ L Brains (Australia)
Person living with EB
- ▶ M Popenhagen (United States)
Psychologist Specializing in EB and Pain - Phoenix Children's Hospital

DEBRA International project team

- ▶ K Mayre-Chilton - CPG patient version project lead (United Kingdom)
CPG Coordinator - DEBRA International
- ▶ O Mullins - Editorial and format lead (United Kingdom)
Business Manager - DEBRA International
- ▶ L A Taguchi - Branding and design lead (Brazil)
Mother of a person born with EB; Marketing Director - DEBRA Brazil
- ▶ M Cardoza - Graphic designer (United Kingdom)

DEBRA International

DEBRA International is the umbrella organisation for a worldwide network of national groups that work on behalf of those affected by the rare genetic skin blistering condition, epidermolysis bullosa (EB). The first DEBRA was created over 40 years ago and is present in over 50 countries around the world.

www.debra-international.org
office@debra-international.org

EB Without Borders

EB Without Borders is a key initiative of DEBRA International. Its mission is to help patients, families, and doctors in countries where there is no DEBRA structure to support them, and to assist new groups to form and develop.

ebwb@debra-international.org

EB-CLINET

EB-CLINET is the global clinical network of EB centres and experts.

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