



OCCUPATIONAL THERAPY

Improving participation in daily activities for children 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.



Charlie Knuth, living with recessive dystrophic EB, aged 13, United States

- ABOUT THIS BOOKLET.....07**
- OCCUPATIONAL THERAPIST (OT).....08**
- ACTIVITIES OF DAILY LIVING (ADLs) 10**
- INSTRUMENTAL ADLS (IADLs) 15**
- USING YOUR HANDS..... 16**
- FINE MOTOR SKILLS.....20**
- ORAL FEEDING SKILLS.....23**
- HELP FROM YOUR CHILD’S OT.....24**
- GET INVOLVED.....26**
- GENERAL INFORMATION.....28**
- CREDITS INFORMATION.....30**
- CONTACT INFORMATION.....32**
- NOTES.....33**
- NATIONAL DEBRA GROUPS.....34**



Iasmin Santos Martin, living with EB simplex, aged 7, Brazil (photo credit: Aline Inagaki for SOS EB Kids)



Who is this booklet for?

This booklet is for parents caring for a child living with any of the following types of EB who are experiencing limitations in their daily activities:

- ▶ 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 improving participation in daily activities for children living with EB. Topics covered in this booklet include:

- ▶ what is an occupational therapist and what do they do?
- ▶ activities of daily living (ADLs)
- ▶ instrumental activities of daily living (IADLs)
- ▶ using your hands
- ▶ fine motor skills
- ▶ oral feeding skills
- ▶ how your child's occupational therapist can help

Where does the information in this booklet come from?

The information and recommendations in this booklet are derived from the "Occupational therapy for epidermolysis bullosa: clinical practice 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 is one type of recommendation in this booklet:



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 29. This patient version also has additional examples to help users understand the variety of tools or equipment they can seek.



What is an occupational therapist and what do they do?

An occupational therapist (OT) helps people to improve their participation in daily activities. They can find ways to change an activity, an environment, or a person's abilities to make participation possible. Living with EB means your child can experience barriers to participating in the activities they value.

An OT helps to:

- ▶ assess your child's daily activities (personal care, eating, education, and leisure and social activities)
- ▶ advise and provide suitable equipment for home, school, and other environments
- ▶ do an assessment of hand function and advise on (custom-made) splints
- ▶ provide advice for schools and other social environments.

An OT can be a life-changing resource. It is important to remember that ideally an OT works with a multidisciplinary team (MDT) including doctors, dietitians/nutritionists, psychologists, physiotherapists, speech and language therapists, social workers, other medical professionals, and, most importantly, with your child.

The medical team must work together to find safe solutions that work for your child as an individual, their body, and their life.



Clara Bodan, living with generalized severe EB simplex, aged 7, United States



“ I can’t walk very well, can hardly hold a pen due to my fingers fusing together... I was able to attend school, graduated from college, passed my driving test, and found my ideal job as a web designer. I felt in control of my condition and my life. ”

Stief Dirckx, born with recessive dystrophic EB, (1978-2018), Belgium

Activities of daily living (ADLs) are basic activities performed by people on a daily basis that are necessary for independent living. These are activities that are needed to take care of your child’s body that are fundamental to living in a social world, enabling basic survival, and well-being.

OTs teach and rebuild the skills people need to maintain, regain, or increase their independence in all ADLs. These activities include bathing and showering, toileting and toilet hygiene, dressing, eating and feeding, and personal hygiene and grooming.

An OT can help your child to become more independent by changing the set-up of their environment, the way they do tasks, or the equipment they use to be able to do these tasks. An OT can also advise you as the carer for your child with EB regarding materials, equipment, and set-up.

Everyone’s needs are different.

Recommendation

If your child is experiencing limitations in self-care or decreased mobility, work together with their OT (and/or MDT) to improve their abilities and quality of life. Working with your child’s OT (and/or MDT) can help your child to get appropriate modifications, adaptations, and recommendations of equipment to help your child’s independence.

There are several types of helpful equipment. The following are some examples but your options are not limited to these alone. Work with your child’s OT (and/or MDT) to find out what is locally available and appropriate for your child. Your child should also receive periodic monitoring of their progress.

Toileting and toilet hygiene

- ▶ Toilet chairs will improve independence by providing additional support to sit down on and get up from the toilet.
- ▶ Soft raised toilet seat cushions or comfort raised toilet seat foam can be used to provide a more comfortable position on the toilet.

Bathing and showering

- ▶ Bath chairs protect the skin from being damaged and allow for safety in the bath or shower.
- ▶ Motorised bath seats or inflatable bath cushions that can deflate can gently lower your child into the bath.

“ He likes to sit in the tub and the problem was I used to have to hold him, and it was very hard and he would slip sometimes. Now with the chair he can immerse himself independently. ”

Mother of a child living with recessive dystrophic EB, United States



Recommendation from the skin and wound care CPG

Do not hold the shower head directly above the skin as this can hurt and damage it. Pour the water onto a sponge and allow it to trickle onto your child's body.



Strong recommendation from the pain management CPG

Providing comfortable measures are recommended to help reduce pain during bathing or showering.



Dressing

- ▶ If your child finds it difficult to use their hands to get dressed or put on shoes, there are a wide variety of tools that are available to help.
- ▶ Clothing materials must be very soft (cotton, rayon, and silk) and ideally with no buttons or seams.
- ▶ Protective dressings can be placed under clothing.
- ▶ Avoid warm clothing or clothes that fit too tightly.
- ▶ Seamless clothing, socks, and underwear can be used to limit rubbing on the skin.
- ▶ *Glidewear* ultra-low-friction fabric is used for clothing, blankets, pillow covers, and other accessories for people living with EB.
- ▶ Double-layer socks use two-layer fabric that protects the skin by gliding smoothly against itself and absorbing friction that can damage the skin.
- ▶ *Kickee Pants* and *Kaysie's Clothing* are other sources of clothing made with extra soft materials for people living with EB.

Recommendation

Infants and children with EB should be encouraged to explore their environments, perform self-care, and participate in activities whilst making sure to minimise the formation of blisters. Knee pads and padded elbow sleeves can be used when your child is crawling. Examples are baby clipper socks, baby-size knee pads, and padded elbow sleeves.



Personal hygiene and grooming

Special tools can improve independence in grooming tasks. Examples are long-handled hair brushes, a hair brush strap, tooth paste dispensers, long-handled sponges, and nail brushes.



Pietro Moura Reis, living with EB recessive dystrophic EB, aged 4, Brazil (photo credit: Suelen Szymanski)



Instrumental activities of daily living (IADLs) are activities to support daily life within the home and community that often require more complex interactions than those used in self-care ADLs, such as care of others, child-rearing, care of a pet, driving, emergency responses, shopping, cooking, home management, going on holiday, and financial management.



Recommendations

- ▶ Anyone living with EB at any age is encouraged to participate in some form of regular physical activity as part of a generally healthy lifestyle.
- ▶ Work with your child's OT (and/or MDT) to get appropriate community support to enable your child to participate in education, and leisure and social activities.
- ▶ Working with your child's OT (and/or MDT) can help determine modifications or equipment needed for greater independence in leisure activities and travel.

What does this mean for your child?

Children with EB can:

- ▶ lead a physically active, healthy lifestyle
- ▶ participate in events
- ▶ go to school
- ▶ participate in leisure, social activities, and travel.

It can be hard to get your child to do daily exercises. Finding ways to make moving more fun can help, for example throwing and catching a soft ball, or playing with bubbles or balloons.

Examples of hand exercises

Work with your child's OT to determine the exercises, methods, and frequency. All hand exercises should be done daily. Length of time and repeats should be individualised to your child's needs.



- 01** Stretch the space between the thumb and the index finger



- 02** Stretch the wrist up



- 03** Stretch the spaces between the fingers

There are also exercise tools that can help your child, for example a gel egg, padded handle with light resistance, and a pliable ball.

Some people with EB are at risk of losing hand function and motion due to scarring, contractures, skin tightness, and pseudosyndactyly (mitten deformities). This has a huge impact on their quality of life. An OT can work to help limit loss of hand motion and strength.

OTs can work with your child at an early stage to try to maximise hand function using non-surgical methods to maintain and optimise the full movement and strength potential of hand joints.

Advice should be individualised to your child's needs. See what your child's local EB team recommends and supports.



Recommendations

- ▶ If your child is diagnosed with recessive dystrophic EB, junctional EB, or Kindler EB, they have a high risk of developing hand deformities. Within the first 1-2 years of life your child's hands must be regularly monitored for deformities by their OT (and/or MDT).
- ▶ Your child will be encouraged to perform daily home exercise programmes including daily active hand "range of motion" (ROM) exercises. This is particularly important for children diagnosed with recessive dystrophic EB and junctional EB.
- ▶ Work with your child's OT (and/or MDT) to monitor developing hand deformities, such as finger contractures and/or finger web spaces getting shorter or creeping together. This may involve measurements of web space/finger length, ROM, and hand function. For preserving the finger web spaces the treatment may involve individual finger wrapping, use of splints, silicone inserts, or silicone moulds.

Hand wrapping

- ▶ Finger wrapping may decrease web space “creep” or closing while still allowing the fingers to be free.
- ▶ Hand wrapping can be done during the day or when your child is sleeping.

The images below show examples of hand wrapping.



Hand splints

- ▶ Hand splints may be used to limit loss of hand motion.
- ▶ Splints can be soft or rigid and can be custom or pre-made.
- ▶ Once your child starts using splints, they may require regular follow-up with a specialist OT hand therapist.

The image below shows an example of a hand and wrist splint.



Check with your child’s OT (and/or MDT) to see if splints are right for them. Splints may be difficult to use. Trying mittens or gloves to prevent web creep can be an option to discuss with your child’s team.

The suggestions in this booklet are non-surgical strategies intended to maintain and optimise the full movement and strength potential of hand joints. If your child’s hands have worsening web creep and/or finger contractures, their OT (and/or MDT) may refer your child to a specialist in hand surgery and post-surgical rehabilitation. Recommendations on this topic are NOT addressed in this booklet; they will be addressed by the “Hand surgery and hand therapy CPG” (estimated date of publication 2020). In the meantime, it is best to work with your child’s OT (and/or MDT) to ensure they receive the best care possible.



Felipe Pliego Pontin, living with recessive dystrophic EB, aged 7, Brazil (photo credit: Suelen Szymanski)

Fine motor skills involve several different hand and finger movements and the coordination to control these movements. Some important skills include having the abilities to grasp and pinch.



Composite full grip



Tip pinch



Lateral pinch

The development of fine motor skills follows appropriate milestones in a child's physical, mental, behavioural, and sensory processing system development. Sensory integration is the process by which we receive information through our senses: we process this information and are able to use it to participate in everyday activities. Many people with EB have difficulty with fine motor skills due to sores and blisters on their hands and decreased finger motion.

Recommendation

Your child should be encouraged to explore their environment to enable the development of age appropriate fine motor skills, support social integration, and improve their quality of life.

OTs can work with your child at an early stage to try to optimise the full movement and strength potential of hand joints to allow functional pinch and grasp for precision, accuracy, coordination, and performance of ADLs tasks. OTs can advise on the choice of toys for babies, tools for doing schoolwork, and ideas for improving the ability to hold things.

OTs can help people continue to be able to perform tasks that require fine motor skills with adaptations as needed.

Tips from the EB Community

- ▶ Encourage your child to hold silverware, pencils and pens, scissors, brushes, etc. even if they need both hands to do so.
- ▶ Encourage your child to play with toys with small parts according to their age; play with play dough, slime, etc.; play musical instruments; paint; do arts and crafts.
- ▶ Encourage your child to minimise the use of tablets, smartphones, and computers because they don't contribute to the use of fine motor skills.



Pietro Moura Reis, living with EB recessive dystrophic EB, aged 4, Brazil (photo credit: Suelen Szymanski)



Sometimes people with EB have difficulty with feeding, eating, and/or swallowing. This can start in infancy and can sometimes continue across the lifespan. Ideally, your child's OT will work with a MDT including doctors, dietitians, and speech therapists to help coordinate the best feeding plan for your child. In some countries, your child's OT will also help with managing swallowing issues.

The medical team managing your child's oral feeding, eating, and swallowing can vary between countries.



Recommendation

Work in partnership with your child's OT (and/or MDT) to obtain appropriate modified tools to improve oral intake, promote inclusion in social interactions, and improve quality of life. Parents of babies with EB can access advice on feeding skills and modifications appropriate for newborns.

OTs are able to help:

- ▶ people learn how to chew and manage food and become more accepting of different textures and flavours
- ▶ improve mealtime experiences at home and in public. Examples are:
 - allowing extra time to chew and swallow
 - taking drinks between bites to help clear the mouth well
 - recommending types of foods that will be easier to chew
- ▶ recommend special tools, such as feeding equipment.

How your child's OT can help

An OT is able to:

- ▶ assess ADLs and provide advice to encourage independence
- ▶ modify equipment to facilitate IADLs
- ▶ advise on suitable equipment for the home, school, and leisure and social environments
- ▶ appropriately train school staff, and other services near your home
- ▶ monitor hand function and try to maximise independent use of the hands and fingers
- ▶ monitor fine motor skills to ensure appropriate milestones of your child's development are met
- ▶ support oral intake of food.

Please contact your national DEBRA group for more information on your local EB specialist clinic.



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

*The panel was honoured with the vibrant work of a wonderful man, Matija Zmazek who sadly passed away at the end of 2018. The involvement and contribution of Matija into the CPGs have made them a great resource that will help many more people living with EB around the world.

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.

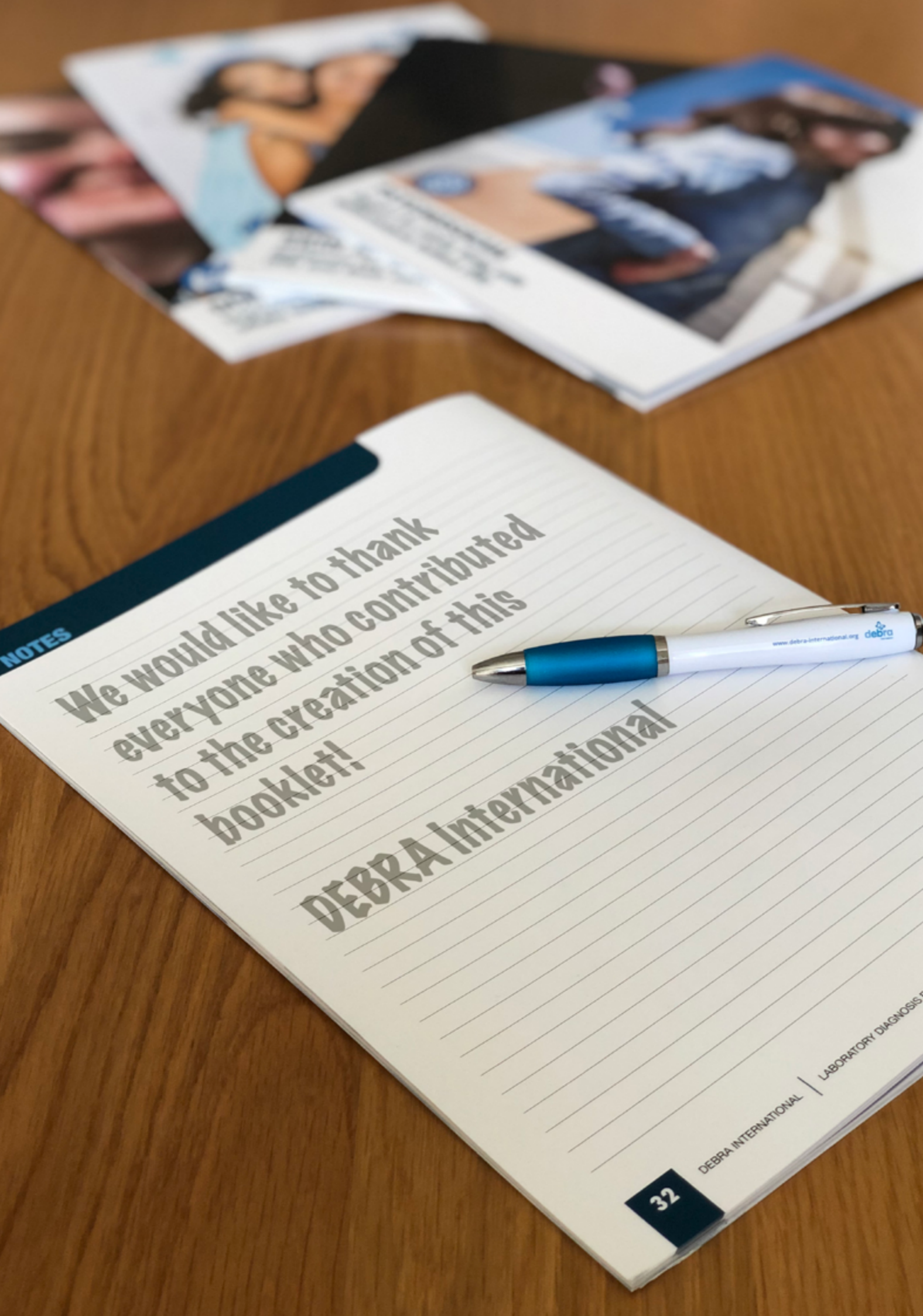
Help us create new CPGs and patient versions

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





Serhan Thompson, living with recessive dystrophic EB, aged 12, United States (photo credit: Ari Espay)

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 of America, 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

Occupational therapy for epidermolysis bullosa: clinical practice guidelines

This CPG was approved by DEBRA International and funded by DEBRA of America.

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



Occupational therapy booklets

Occupational therapy improving participation in daily activities for adults living with epidermolysis bullosa (EB)

Other CPG topics referred to in this booklet



International Consensus Best Practice Guidelines for Skin and Wound Care in Epidermolysis Bullosa



Pain care for patients with epidermolysis bullosa: Best care practice guidelines

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
- ▶ Oral Health Care for Patients with Epidermolysis Bullosa - Best Clinical Practice Guidelines
- ▶ Psychosocial recommendations for the care of children and adults with epidermolysis bullosa and their family: evidence based 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 Occupational therapy guideline produced?

- ▶ The CPG development group consisted of EB experts: occupational therapists, hand therapists, a physiotherapist, a paediatric dermatologist, a community social support lead, 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 occupational therapy 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 occupational therapy research together with the personal experiences of the panel members.
- ▶ To identify publications, eight electronic search engines were accessed, including Medline (PubMed MeSH), Embase Emtree PsychInfo, CINAHL, Scopus, and the main search engine for the National Institute for Health and Care Excellence (NICE). Searches were performed using the terms "EB and occupational therapy" and "EB and 25 interventions" with the search period ending December 2018.
- ▶ Out of 70 papers appraised, 20 were chosen for the final recommendations by nine panel members according to the Critical Appraisal Skills Programme (CASP) and Scottish Intercollegiate Guidelines Network (SIGN) quality rating.

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THE WORLD'S LEADING EB PATIENT ADVOCACY AND SUPPORT NETWORK

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