

Occupational Therapy Guideline: Additional file 4

International EB Camps and Activities Directory

Host	Name of the activity	Type of activity	Target groups	Location	Contact
DEBRA of America					
	debra Care Conference	This is a multi-day event made specifically for EB families and the professional community to access the best information, discover new ideas and connect with other EB families from all over the country Different rate packages for EB families, non-EB families, professionals.	EB families and the professional community	Location changes in USA	http://www.debra.org/debra-hosted-events
DEBRA Argentina					
	Occupational therapy (OT) service	OT service only at the DEBRA House, not outreach service. In Spanish only	All ages and family	DEBRA House	www.debraargentina.org
DEBRA Australia					
	Kids Camp and Conference	Every 2-3 years this is a great opportunity to network with other families and learn all things EB. The children have an amazing time and make lifelong friendships. Registration fee has been heavily subsidised by DEBRA	Families living with EB, and any extended family	Location changes in Australia	https://www.debra.org.au/family-support/national-eb-camp/

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DEBRA Austria					
*	Family weekend	Time out of daily life, exchanges of experiences. Main language is German, members also from Italy. No fee to attend to members only.	All ages and family	Location Ainring in Germany	Sabine Wittmann, DSA Sabine.Wittmann@debra-austria.org 0043/1/8764030-0
	Annual DEBRA Austria Meeting	Trainings for people with EB and their relatives; Social program; Exchange of experiences. Main language is German, members also from Italy and Germany. DEBRA Austria pays most of the expenses (only the drinks at meals have to be paid by the members).	All ages, members and their families	Salzburg Austria	Sabine Wittmann, DSA Sabine.Wittmann@debra-austria.org 0043/1/8764030-0
DEBRA Chile					
	Holiday Break in the national country	A group of thirteen EB patients' families are invited with everything included to a week of holidays in La Laguna beach. 41 people. DEBRA Chile absorb all the costs for members only	All ages and their families	Región de Valparaíso, La Laguna, Chile	Ana María Gonzalez amgonzalez@debrachile.cl +56993386091

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DEBRA Germany					
	Annual Weekend Families	Family-feel with workshops and fun events for children	EB families with young children	Location changes in Germany	ieb@ieb-debra.de www.ieb-debra.de
	Annual Weekend for Mothers	Respite for mothers	Mothers with children with EB	Location changes in Germany	ieb@ieb-debra.de www.ieb-debra.de
DEBRA New Zealand					
*	Adventure/snow camps	The camps are run approximately every 2 or 3 years, depending on who is interested in organising and how many are interested in attending.	People with EB	Location changes in New Zealand	debra@debra.org.nz
	Family camps	Emphasis on fun family activities.	EB families with young children	Location changes in New Zealand	debra@debra.org.nz
DEBRA Slovakia					
	Holiday Break Abroad	Patients and their families go on one week vacation by the sea to heal the wounds and the skin. Not every year depending on who is interested and its members only.	All ages and their families	2014 Spain 2015 Croatia 2016 Bulgaria	http://www.debra-slovakia.org/ Kristína Ficeriová kristina.ficeriova@gmail.com +421911793945

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DEBRA Slovakia					
	Camp	Patients and families meet annually to be informed about the last year's activities, presenting new materials for EB patients, latest information about EB research, sharing experiences. For members only and the organisation absorb the costs of accommodation, catering, meeting activities	All ages and their families	Slovakia Every year somewhere else	Kristína Ficeriová kristina.ficeriova@gmail.com +421911793945
DEBRA Spain					
*	Annual DEBRA Spain Family Meeting	It includes talks and workshops and activities for people with all types of EB and all ages. Main language is Spanish. It is available to anyone. Members of DEBRA Spain have a grant to attend and people from outside must pay their expenses (hotel and meals).	All ages and their families	Madrid Spain	Evanina de Morcillo Makow info@debra.es 00 34 952816434

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DEBRA Sweden					
	Camp	Camp for all members annually	All ages and their families	location, activity and time of year varies	www.ebforeningen.se
DEBRA United Kingdom (UK)					
	Annual Overnight Weekend	Family-feel with workshops and fun events for children	All ages	Location changes in UK	Helen Weaver helen.weaver@debra.org.uk
	Supported Weekend City Break	Encourage independent living, peer-support and networking with medical and peers	Adults with severe EB	Location changes in UK	Helen Weaver helen.weaver@debra.org.uk
	Four holiday homes	Holiday homes adapted for use by people with EB	All ages	UK	Helen Weaver helen.weaver@debra.org.uk

Key: * The activity welcomes people from other countries, do check their conditions.

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Others none-DEBRA EB Camps and Activities

Host	Name of the activity	Type of activity	Target groups	Location	Contact
Brazil					
	Dermacamp	Camp for children with skin diseases, they have large experience with EB	Children with skin diseases	São Paulo, Brazil	http://dermacamp.org.br
United States					
	SeriousFun Camps	Host family weekends and week-long kids-only summer camps and typically have medical/nursing staff available for both.	Family and kids-only	Location changes in USA	https://www.seriousfunnetwork.org/
	The Center for Courageous Kids in Kentucky	Similarly to the SeriousFun Camps but is independent of that organization.	Family and kids-only	Kentucky USA	http://www.courageouskids.org/
	Camp Discovery Program by The American Academy of Dermatology's (AAD)	Under the expert care of dermatologists and nurses, Camp Discovery gives campers the opportunity to spend a week with other young people with skin conditions having fun. No fee to attend.	Children ages 8-16 who have a chronic skin disease	Location changes in USA	https://www.aad.org/public/kids/camp-discovery

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United States					
	Camp Spirit	The Colorado Winter Adventure Camp provides opportunity to enjoy winter activities in a safe environment. No fee to attend.	Children ages 9-18 with Recessive Dystrophic EB (RDEB)	Colorado USA	https://campspiritcolorado.org/
	Camp Wonder Program by The Children's Skin Disease Foundation's	This is dedicated to providing a safe and nurturing environment to children with a skin disease. No fee to attend.	children ages 7-16 living with a skin disease	Location changes in USA	https://www.csdf.org/camp-wonder

Key: * The activity welcomes people from other countries, do check their conditions.