

OCCUPATIONAL THERAPY FOR PERSONS LIVING WITH EPIDERMOLYSIS BULLOSA

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What is Occupational Therapy?

- OT helps people who have limitations due to disease, injury, or disability to improve their participation in daily activities. In simpler terms, “helping people do what they need and want to do in their daily lives”
- An occupational therapist ideally works as part of a multidisciplinary team to help meet the medical needs of a person with EB

How Can OT Help Persons with EB

1. Change how something is done
2. Modify the environment
3. Improve a person's abilities to help make participation possible
4. **Share ideas from others**
5. **Encourage people to try new things in new ways**

Review of OT Clinical Guideline Recommendations

1. Maximization of hand function-non-surgical
2. Activities of daily living (ADL)- relating to self care
3. Instrumental ADLs-more complex than basic ADLs and includes living independently, working, driving, going to school and caring for children
4. Fine motor development and retention
5. Oral feeding skills

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Maximization of Hand Function

1. Hand Function and Quality of Life in Children with Epidermolysis Bullosa (Eismann et. al., 2013)

“ QOL shown to be highly related to the degree of hand function with a significant correlation of the Quality of Life.”

2. Hand Surgery and Hand Therapy Clinical Practice Guideline for Epidermolysis Bullosa (Box et. al., 2022)

“Improvement in hand function is temporary, with recurrence expected within 1–2 years, 50–53% occurring after 1 year, with approximately 50% requiring further procedures”

What Methods of Intervention Optimize Hand Function



Independence in ADLs



Toothpaste dispenser



Elevating bath seat



Bidet toilet seat

Quality of life and Independence in Activities of Daily Living in Epidermolysis Bullosa

(Chan, J., Segovia, N., Ladd, A. 2020)

Cross sectional study

Subjects: persons with RDEB aged 9-25 years

Purpose: correlation of independence in ADL and QOL (QOLEB)

19 subjects 2014-2017

Findings:

- Slight positive trend in correlation of independence in self care and QOL

Recommendations:

- More subjects
- Use assessment tool that allows subject to give a value to specific ADLs and IADLs
- Include leisure activities

Anecdotal evidence that IADLs are more important and may have greater impact on QOL

- Driving
- Living independently
- Working
- Participating in leisure activities

Driving Ideas shared by Rachel Nasuti



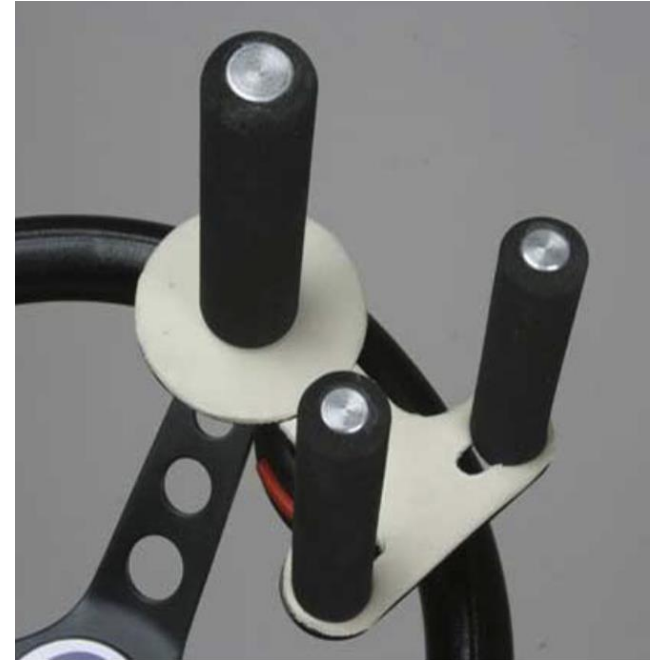
Padding straps



Using cat collars on handles
Erasers on window buttons



Wedge foot rest



Tripin steering wheel attachment

Living Independently

Debra of America Care Conference 2024

Adaptive Equipment:

https://docs.google.com/presentation/d/1zhv9_OIYFVSh6j3NpoEcHt21X2-RDp20xWESMUf73QI/edit?usp=drive_link

You tube interview with Henry George:

<https://www.debra.org.uk/henrys-story>

Activities and Outings

Camps in the U.S.

- Camp Discovery: Week-long camp in various locations for children aged 10-16 with serious skin conditions
- Camp Wonder: Summer camp for children with serious skin conditions aged 6-16 residing in the US
- Camp Spirit: A Colorado-Based winter Camp for children ages 9-18 with RDEB

Activities and Outings

Debra UK

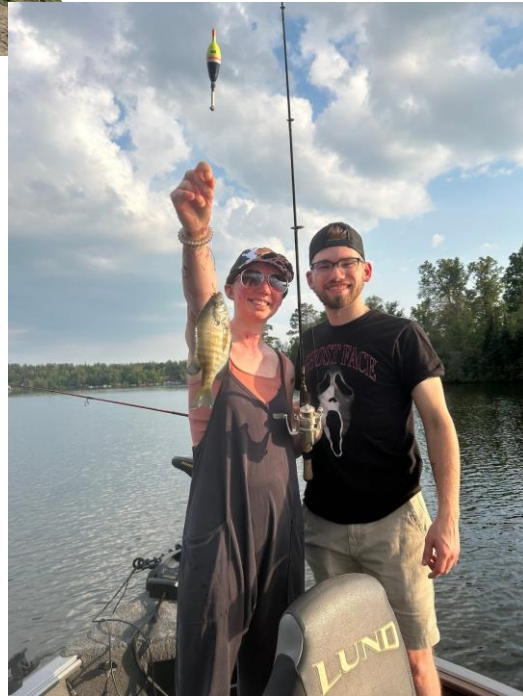
- Annual overnight weekend including a theme park day
- Supported weekend city break (London 2023 plans for 2024)
- Working on an adults-wellbeing weekend
- Holiday homes. (Now up to 7 homes – two are in one location so 2 families with EB can go at the same time)
- Events for Teens (Harry Potter tour and Scotland Festival)

Community Events

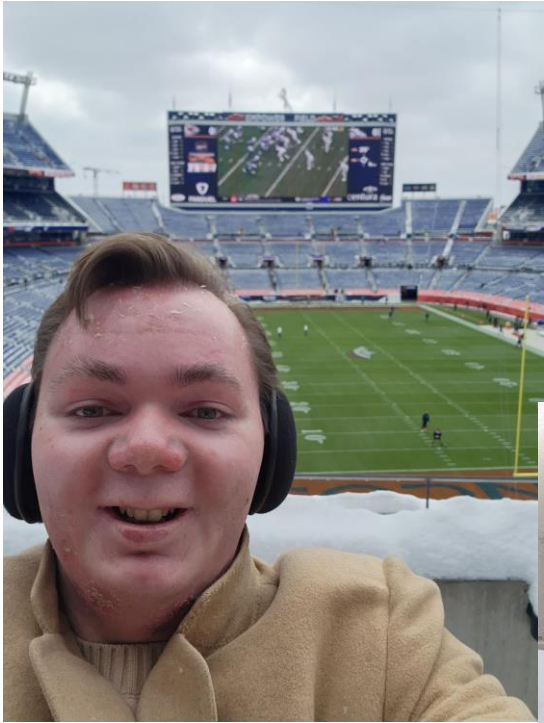
Debra Care Conferences:

- Austria
- Australia
- Chile
- Germany
- New Zealand
- Slovakia
- Brazil
- Sweden
- Spain
- Bulgaria

Faith Smith



Henry DeAngelis



Amora Matteson



Recommendations

1. Further research on best practices to maximize hand function
2. Create a directory of adaptive aides and equipment to support ADL and IADLs
3. Update list of recreational activities and camps available to persons with EB around the world

References

Eismann E, Lucky A, Cornnwall R. Hand function and quality of life in children with epidermolysis bullosa. *Pediatr Dermatol.* 2014;31:176-82.

Box R, Bernardis C, Pleshkov A, et al. Hand Surgery and Hand Therapy Clinical Practice Guideline for Epidermolysis Bullosa. *Orphanet J Rare Dis.* 2022.

Chan, J., Segovia, N., Ladd, A. (2020). Quality of Life and Independence in Activities of Daily Living in Epidermolysis Bullosa.

Research Square, 1-10. <https://doi.org/10.21203/rs.3.rs-41738/v1>.

Adaptive Equipment:

[https://docs.google.com/presentation/d/1zhv9_OIYFVSh6j3NpoEchT21X2-RDp20xWESMUf73QI/edit?usp=drive link](https://docs.google.com/presentation/d/1zhv9_OIYFVSh6j3NpoEchT21X2-RDp20xWESMUf73QI/edit?usp=drive_link)

Thank you!



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