

Message from our Chief Investigator Professor Jemima Mellerio

As we come towards the end of the year, I'd like to take the opportunity to extend a very big thank you for your participation in PEBLES.



We have grown now to over 60 participants and over 360 individual reviews in the study and we are starting to get some really interesting results from our analysis of the data on itch, pain, quality of life and costs of care.

2023 will bring more analysis which we will feed back to you through these newsletters and from the PEBLES team when we see you. All this is only possible because of your time and willingness to take part, for which we are enormously grateful. We wish you a very happy festive season and look forward to a happy and productive PEBL-ing year ahead!

Jemima

PEBLES is expanding to Europe

DEBRA Austria have agreed to fund the expansion to 2 new sites, Austria and Germany, over the next 12 months. This will include adult and child participants.

We need to translate all PEBLES documents into German and complete approvals in all three countries before recruitment can begin. We hope to recruit our first adult or child at each site before end 2023.

Thank You DEBRA UK

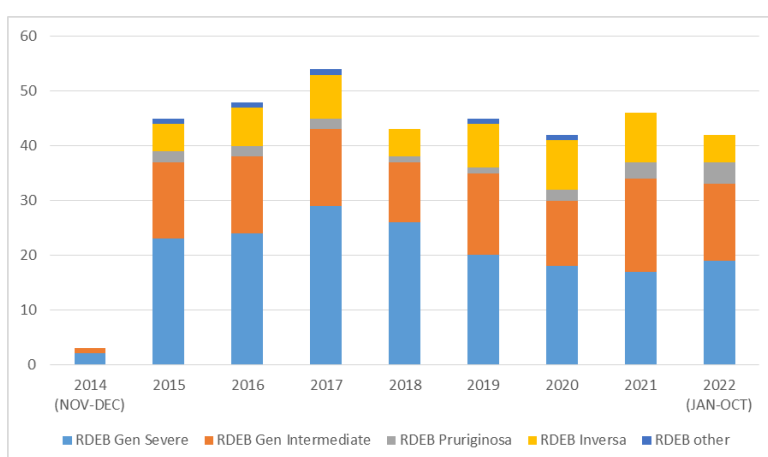
The PEBLES Team would like to say a big thank you to DEBRA UK for funding the study from 2014-2022!

PEBLES was commissioned back in 2014 by DEBRA UK who recognised the importance of a detailed natural history study of RDEB which could be used to inform future trials of treatment for RDEB.

Visionary DEBRA UK Research Directors were behind the inception of the project and have supported us for many years, not only with funding, but a continued belief in the value of the information produced by PEBLES to those proposing new therapies for RDEB.

As PEBLES continues to grow and we transition to our new sponsor DEBRA Austria, we would like to recognise the important role DEBRA UK has played in making PEBLES possible for over seven years.

Annual Reviews by RDEB Subtype



This chart shows the number of reviews conducted each year and the different colours indicate RDEB subtype. As of October 2022, 368 reviews have been completed since PEBLES started in late 2014.

Itch Paper

We've just submitted our first paper for publication, reporting itch in RDEB. Here's a quick summary of the Itch Paper.

Itch is common and distressing, occurring in all forms of EB, and tends to relate with disease severity. Despite various treatment approaches, benefits are usually minimal at best.

Itch had not previously been studied in depth in different RDEB subtypes. In our PEBLES study, 50 individuals with RDEB aged 8 years and above completed the Leuven Itch Scale (LIS) providing a total of 243 reviews over a 7-year period.

Itch was shown to be present and frequent in the preceding month in 93% of these reviews. Our data shows a variety of differences in itch symptoms between RDEB subtypes. The RDEB severe and pruriginosa groups reported greater severity and frequency of itch.

Itch symptoms were related to symptom severity scores and quality of life for RDEB intermediate and inversa, but not for RDEB severe.

Despite high frequency of itch, many patients don't use any itch treatment which shows an unmet need for better therapy options.

Severity Scores and Skin Assessment

Severity Scores play an important role in the analysis of PEBLES Data. We will use these for comparison with costs of care, pain, quality of life, etc., so it helps to have complete scores where possible.

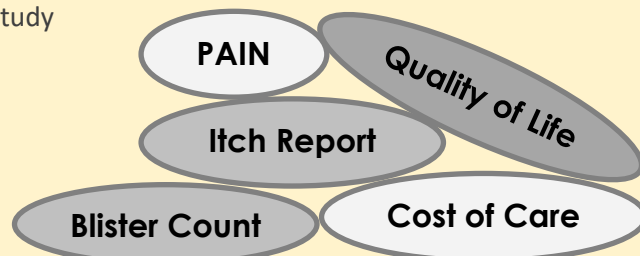
Two key scores (BEBS, iscorEB) both include skin severity ratings in addition to other markers of severity such as changes to your mouth, hands, eyes, etc. We also compare this with quality of life scores to see the impact of RDEB on daily life and functions.

For us to complete the skin scores, we need to either see your skin or use recent photographs of your skin. We do rely on the photos you provide, so thank you for each photo you give us!

We have created a guide to safely transferring your photos using EGRESS. (See guide sent with this Newsletter)

The guide on how to do your photos is at the back of your Review Booklet. We securely store your photos on GSTT hospital computer server, identified only by your research ID number.

Your PEBLES Booklet collects important data for the study



We try to collect your completed booklet at each review visit to include your data in our analysis. Your PEBLES Research Nurse can help you complete and return your booklet to us.

Reporting Costs, Pain and Quality of Life

Three more papers on issues of great importance are being prepared for publication, using information collected from your booklets:

1. **Costs of community care, focusing on wound dressings and carer costs.**
2. **Pain**
3. **Quality of life**

We will give summaries in future newsletters.

PEBLES in Numbers (Jan-Oct 2022)

3 New Adult Participants

1 New Child Participant

42 Reviews completed

Research ID & Review number: _____

Please tick each box as you take your photographs

1	Trunk front	<input type="checkbox"/>
2	Trunk back	<input type="checkbox"/>
3	Right arm front	<input type="checkbox"/>
4	Right arm back	<input type="checkbox"/>
5	Left arm front	<input type="checkbox"/>
6	Left arm back	<input type="checkbox"/>
7	Right hand back	<input type="checkbox"/>
8	Right hand palm	<input type="checkbox"/>
9	Left hand back	<input type="checkbox"/>
10	Left hand palm	<input type="checkbox"/>
11	Right leg front	<input type="checkbox"/>
12	Right leg back	<input type="checkbox"/>
13	Left leg front	<input type="checkbox"/>
14	Left leg back	<input type="checkbox"/>
15	Right foot dorsum (top)	<input type="checkbox"/>
16	Right foot sole	<input type="checkbox"/>
17	Left foot dorsum (top)	<input type="checkbox"/>
18	Left foot sole	<input type="checkbox"/>
19	Face	<input type="checkbox"/>
20	Scalp	<input type="checkbox"/>

IRAS 142032, Patient booklet Adult 21 years and over v3.0, 6th April 2021

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