EB Expert Panel Workshop Report

20th May 2023
Grand Canal Hotel
Dublin

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About Debra

We are Debra, the butterfly skin charity.

We might be a small charity, but make no mistake, our mission and our ambitions are colossal. We are here to tell Ireland and the world beyond about Epidermolysis Bullosa (EB) - a painful and distressing genetic disorder that affects the body's largest organ; the skin.

We are here to be a positive force for all those living with EB and all those whose lives have been impacted by EB. Our key working areas include EB Support, Advocacy and Research. We are here to help in all kinds of every day ways, to listen, support, empower and alleviate unimaginable pressures. We are here to lobby those in the halls of power. To command attention, demand and drive research and ensure imperative progress is made.

But above all, we are here to bring hope - not that passive, powerless, resigned kind of hope - but the active bold hope that moves things on.

Uniting for change for everyone with skin as fragile as a butterfly wing.

About the EB Expert Panel

We know that there is power in numbers. The more voices we have the stronger our work will be. In November 2022, we launched our EB Expert Panel, a group of those who understand EB the most and are willing to use their experience to shape our work.

The panel advise us on various topics related to what living with EB in Ireland is like now and what it should look like in the future. With their help, we can make sure we can provide support in the way that matters to them. As valued advisors, members of the EB Expert Panel provide advice to our Research, Advocacy and Family Support teams on projects they are working on.

The panel meets as a group twice a year. In between meetings, participants stay connected with Debra through one-on-one conversations with our team, when their advice is needed.

We would like to sincerely thank all members of the EB Expert Panel for their valued contribution to our work. We look forward to working with you further.

Opening Remarks

Eve O'Donnell - EB Support

Eve opened the workshop by introducing herself and other members of the Debra team who would be managing the EB Expert Panel and facilitating the workshop; Kate Gibney, Sarah Mullins, Sinéad Hickey, Joanna Joyce and Marina Shatskikh.

She thanked those attending for giving up their Saturday in order to make a difference to the work carried out by Debra.

For any new members of the panel, she explained the purpose of the EB Expert Panel and how they can help the Debra team. She then went on to remind the panel that they meet for a workshop twice a year to discuss bigger topics as a group, with individual panel members being contacted directly on an ad-hoc basis in between workshops for smaller tasks.

All members of the panel are offered payment for tasks they complete, including workshop attendance, with payment levels based on the time and effort it takes to complete a task. Eve thanked those who had returned after attending the first workshop in November 2022 and welcomed those who were attending their first workshop on the day.

After her opening remarks, Eve went over some house rules for the workshop and asked everyone to introduce themselves during a short icebreaker activity. She then handed over to Kate and Sarah, who were providing the Family Support and Research updates since the last meeting.

Updates

Kate Gibney - EB Support

Kate provided an update on the progress of the 'EB Hub' which was discussed at the last EB Expert Panel Workshop. The online EB Hub will be a platform to easily access information and support for EB.

Kate thanked everyone for their input in Phase 1 of the project, which was the initial discussion with the panel to get ideas for the hub. These ideas have helped the Family Support Team (FST) in identifying further needs and priorities for the hub.

Two topics of high priority will be focused on in Phase 2, psychological wellbeing and healthcare.

Kate explained that many resources already exist for EB in this area, so Phase 2 will involve gathering all information that is already available.

The FST will then be reaching out to the panel to get feedback on whether these resources are applicable to an Irish audience and to help them make adaptions if necessary. This scoping exercise will also help FST assess any gaps that need to be addressed by the hub.

Updates

Sarah Mullins - Research

Sarah provided an update on Debra's Research Priorities and Criteria, which the panel worked on at the last workshop. Sarah explained for any new members, that at the last meeting, the panel were shown Debra's Research Priorities and Criteria which had been decided by individual's who took part in a Debra survey many years ago.

The Research Team had previously been using this list of research priorities to guide the research they chose to support, but felt it may need updating. Through group discussions the below updated research priorities were established.

Research Priorities before last workshop...

- Wound Healing
- Gene Therapy
- Pain Management
- Cell Therapy
- Medical Devices

Research Priorities after last workshop...

- Wound Healing
- Gene and Cell Therapy
- Pain Management
- Psychosocial/Mental Health Studies
- Medical Devices - with a particular focus on feet

Sarah explained that the Research Team will now be using the updated version of the Research Priorities to inform their work and help them to priortise which areas of research Debra should support. She also thanked the panel for their feedback at the last workshop.

Research

In recent times, the Research team has had the opportunity to increase the amount of research being carried out about EB in Ireland. Before this, only one research group, led by Prof Wenxin Wang in UCD, was carrying out research on EB in Ireland. The Research team were delighted to introduce the below researchers and the projects they are working on to the EB Expert Panel.

Dr Irene Lara-Sáez, UCD - A pain and wound management approach for RDEB patients via a functionalized collagen-based hydrogel dressing with controlled release of painkillers.

Dr Joanna Sadowska, RCSI - Gene-activated scaffolds for the treatment of Epidermolysis Bullosa.

Dr Zohreh Mousavi Nejad , DCU - A nanoparticle-loaded hydrogel for Epidermolysis Bullosa (reGENErate).

Laura Trujillo Cubillo, UCD - Epidermolysis bullosa: Development of advanced biomimetic living equivalents (EB-DOABLE).

After their presentations, each researcher sat at one of four discussion tables with 3-4 EB Experts and a facilitator from Debra. Together, the EB Experts and researcher worked on revising their project lay summary to ensure it was understandable to those living with EB, their families, their carers and the general public.

A lay summary is a brief summary of a research project that has been written for members of the public, rather than researchers or medical professionals. All original lay summaries and the amended versions can be seen on the following pages.

Project Title: A pain and wound management approach for RDEB patients via a functionalized collagen-based hydrogel dressing with controlled release of painkillers.

Primary Investigator: Prof Wenxin Wang, University College Dublin (UCD)

Original Lay Summary

Recessive Dystrophic Epidermolysis Bullosa (RDEB) is an inherited disease affecting the skin. Children born with the disease are called 'butterfly children' as their skin is seen to be as delicate and fragile as that of a butterfly's wings. We propose a research program that will address the significant problem of wound healing and pain management in RDEB patients.

The goal of this proposed project is to develop an advanced dressing system for the treatment of RDEB wound, which function not only as a wound healing device but also as a local release device for the delivery of painkillers.

The basis of this wound dressing will be a miniature injectable hydrogel device known as collagen-based hydrogel. Collagen is one of the main components of the skin; thus, this hydrogel mimics the properties and microenvironment of normal skin. The hydrogel is loaded with pain killers which will be released from the hydrogel directly into the wounds soothing the pain. The hydrogel can be applied by injection through a syringe or tube to wounds and cover and protect the wound site. The dressing can be easily removed from wound site by simply washing the wound area. Pain can be caused by the areas of skin loss, wounds and dressing changes.

By applying the pain killer loaded hydrogel dressing, pain killers will be slowly released from the hydrogel in a controlled manner. Thus, painful interventions will be managed by easily applying a gel on wound site. One major outcome from this proposed project will be the development of a new generation of wound dressing in combination with a topical painkiller that is capable of promoting wound healing while reducing pain.

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Project Title: Gene-activated scaffolds for the treatment of Epidermolysis Bullosa

Primary Investigator: Prof Fergal O'Brien, Royal College of Surgeons Ireland (RCSI)

Original Lay Summary

Epidermolysis Bullosa (EB) is a rare genetic skin condition affecting about 1 in every 30,000 babies worldwide and 1 in 18,000 children born in Ireland. In patients with EB, defective genes make the skin extremely fragile, causing it to tear or blister from even the slightest touch. EB is also associated with many other health complications.

In this project, we propose a unique approach combining gene therapy to fix the defective gene with tissue engineering to create special biomaterial scaffolds. These scaffolds will help heal EB skin tears or wounds. Our idea is to develop a gene-activated scaffold as a ready-to-use treatment for EB wounds, which will act as a protective dressing and potentially fight bacteria for external wounds and blisters.

Typically, gene therapy uses viruses to deliver genes to cells, which can raise safety and regulatory concerns. Instead, we will create a "gene-activated scaffold" containing tiny particles with the corrected forms of the defective genes. These particles will safely and efficiently deliver the corrected genes to the target cells. After obtaining promising preliminary data from this project using two- and three-dimensional lab models, we will apply for funding for a larger grant to test these scaffolds in living organisms.

Our ultimate goal is for the gene-activated scaffolds to be placed into an EB skin wound, where the patient's own cells will move into the scaffold, pick up the tiny particles, and start using the corrected gene to improve healing.

Reducing wound severity, risk of infection, and speeding up wound healing are top priorities for patients with EB and their caregivers. Our research aims to not only reduce wounds but also provide antimicrobial properties to prevent infections. Thus, our ready-to-use gene-activated scaffolds could promote successful wound healing in EB patients while minimising infection. This improved wound healing and reduced infection risk may also help prevent other complications.

As we progress from the pilot project to a larger follow-up study, Patient and Public Involvement (PPI) will become a major focus of our work. We will collaborate with patient advocates, caregivers, and clinicians to shape this research in meaningful ways. This includes deciding which type of EB to test the gene-activated scaffolds on, designing the project evaluation, and determining the best ways to communicate the research process and outcomes to patients and health policy.

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Typically, gene therapy uses viruses to deliver genes to cells, which can raise safety and regulatory concerns. Instead, we will create a "gene-activated scaffold" or "patch" containing tiny particles with the corrected forms of the defective genes. These particles will safely and efficiently deliver the corrected genes to the target cells. After obtaining promising preliminary data from this project using two- and three-dimensional cells, we will apply for funding for a larger grant to test these patches in living organisms.

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Project Title: A nanoparticle-loaded hydrogel for Epidermolysis Bullosa (reGENErate)

Primary Investigator: Prof Nicholas Dunne, Dublin City University (DCU)

Original Lay Summary

Epidermolysis Bullosa (EB) encompasses a group of debilitating medical conditions characterized by fragile skin prone to blistering and delamination due to a weak interface between the dermis and epidermis. In dystrophic EB patients, the primary cause is often a deficiency in the expression of collagen VII, a critical component of anchor ring fibrils that connect the basement membrane of the dermis to the epidermis.

Currently, the localized treatment of EB faces challenges such as low transfection efficiency and the difficulty of delivering genetic material deep into the skin. The skin's structure impedes the penetration of larger molecules, making effective delivery a significant obstacle.

To address this issue, our proposed solution is to deliver genetic cargo encoding collagen VII. Two types of genetic cargo will be compared: (i) mRNA, which offers direct translation to a functional protein, reduced risk of genomic integration, but requires more frequent administration, and (ii) CRISPR, which can result in long-term overexpression but carries risks associated with genetic editing.

To facilitate cellular uptake of the genetic cargo, we will utilize a peptide called RALA, known for its ability to condense genetic material into nanoparticles. These RALA/Collagen VII nanoparticles will be incorporated into a nanogel system. The nanogel is a smart, polymer-based material that is biocompatible and sensitive to changes in the wound environment. It is designed to be water-biodegradable and will offer a safe and effective means of delivering therapeutic cargo.

By addressing the challenges of transfection efficiency and effective delivery of genetic material, our innovative approach holds promise for improving the treatment of EB. The development of this nanogel-based system paves the way for a more effective and patient-centred treatment option for individuals suffering from EB.

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Currently, the specific treatment of EB faces challenges such as the difficulty of delivering genetic material deep into the skin and poor delivery effectiveness. The skin's structure impedes the penetration of larger molecules, making effective delivery a significant obstacle.

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To facilitate cellular uptake of the collagen VII, we will use a peptide carrier called RALA, known for its ability to condense genes into smaller particles, known as nanoparticles. These RALA/Collagen VII nanoparticles will be incorporated into a nanogel system. The nanogel is a smart, polymer-based material that is not toxic and sensitive to changes in the wound environment. It is designed to be water-biodegradable and will offer a safe and effective means of delivering collagen VII.

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Project Title: Epidermolysis bullosa: Development of advanced biomimetic living equivalents (EB-DOABLE)

Primary Investigator: Prof Dimitrios Zevgolis, University College Dublin (UCD)

Original Lay Summary

Epidermolysis Bullosa (EB) is a rare genetic and incurable disease that is associated with severe and painful skin and mucosae fragility, which results in blisters and erosions. It is estimated that 1 per 50,000 live births are diagnosed with EB and that 1 per 100,000 people have the disease. Its severity ranges from mild to fatal and affects every racial and ethnic group worldwide and both sexes equally.

The market size of EB in seven (USA, UK, Germany, France, Italy, Spain, Japan) major markets is estimated at US$ 2,283.40 million per year, with compound annual growth rate of 5.67 %. Although cell-based tissue engineering therapies have shown remarkable clinical safety, efficiency and efficacy, no product has been commercialised (they are at various stages of clinical trial assessment).

This limited technology transfer from bench-top to clinic has been attributed to the prolonged cell culture time required to develop marginally functional and three-dimensional implantable devices.

This lengthy culture period not only results in cellular phenotype, function and therapeutic potential losses, but also is associated with very high manufacturing costs.

We have developed a patent-protected technology, termed macromolecular crowding, that enables the accelerated (days as opposed to months) development of functional and truly three dimensional living substitutes. EB-DOABLE will assess the potential of macromolecular crowding in naïve and engineered to synthesise collagen type VII cell populations, ultimately allowing for the development of functional therapy for EB. EB-DOABLE is a collaborative project between the University College Dublin and the University of Alberta.

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Amended Lay Summary

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We have a model of the skin environment in the lab that we want to apply to EB skin. The model is made up of skin cells that are packed really tightly together with other molecules that are found in the skin.

The reason for packing the cells and molecules really tightly together is to ensure they behave the same way as when they are packed together in the skin and the molecules can find each other and react the same way they would in the skin. This is called macromolecular crowding. We are going to assess the potential of this model to create functional collagen 7. If it works, it can potentially be applied to DEB wounds to heal them.

This type of model makes it faster and cheaper to make commercially because the macromolecular crowding allows for the skin model to develop faster and reduced the manufacturing time compared to other skin models.

If this works for collagen 7 and DEB the same technology can potentially be applied to other types of EB.

EB-DOABLE is a collaborative project between the University College Dublin and the University of Alberta.

We have updated our brand

We may have changed how we look but we are still the same.

Brand is everything people see, think, and feel about us as an organisation. It's the space we occupy in someone's mind. It's the thread that links everything we do.

Over the last 6 months, we have been working hard to refresh our brand and make it more relevant, accessible and in line with what we want to achieve for people living with EB, caring for someone living with EB, or bereaved by EB.

Our current brand has been in existence for a long time and, in that time, Debra and the society we operate in have changed. We wanted our look and feel to be as strong as what we do.

This is why, with the help of people living with EB and those caring for someone with EB, we took the time to look into what could be done differently in order to stand out as the mighty organisation we are. Some of our EB Experts were involved in this process so we gave them a sneak peek of our new look. We thanked them for their help with some delicious cupcakes showcasing our new logo.

Advocacy

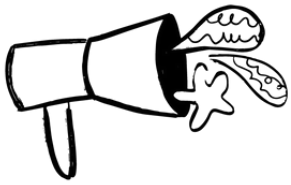
Joanna Joyce - Head of Advocacy

Joanna explained to the panel that Advocacy is about raising awareness of EB, influencing those in power and creating change that has a meaningful impact on people's lives. The focus of Debra's advocacy work is to advocate alongside families to ensure their voices are heard, and to ensure that they receive the right services and supports at the right time. Debra's vision for the future is that all families living with EB have access to all of the services and supports that they need as a matter of right, not based on where they live, how supportive their local HSE manager is or how much they engage with Debra. To do this, Joanna described how advocacy work needs to be structured and evidence-based, so we can focus on the areas where we can have the most impact and strongly advocate in these areas with this evidence. We need evidence to convince Government and other policy makers to invest in and prioritise EB. We create this evidence through collaborative projects through our advocacy and research teams.

Joanna then went on to talk about 'The Butterfly Review'. This is an advocacy-based research project that will take place over a number of years. The aim of this project is to deliver a national review of current EB services and supports for those who live with EB in Ireland, with a view to developing an agreed blueprint for the future of EB services in Ireland. This approach has worked very well in other areas of health, such as 'The Pollock Report' for Cystic Fibrosis.

Joanna then asked the EB Experts to break out into two groups in order to complete the advocacy activity. This involved the EB Experts writing their thoughts on sticky notes to outline the gaps they have seen in EB services and supports currently available in Ireland. A Debra facilitator then grouped the sticky notes into themes which were fed back to the wider group.

Advocacy



Group One - Gaps in current services/supports

Access to resources

- Financial support for footwear.
- Medical card.
- Free travel pass to assist with walking.
- Short-term prescriptions.
- Cost of creams and additional treatments.
- Blue badge (for parking).
- Access to dressings.

Mental health

- Mental health support/ support for living in family dynamics with EB.
- Could mental health support link in with secondary school/ college/ community to check in on people every so often?

Access to medical professionals

- Night nursing service.

Medical staff capacity and knowledge

- Public Health Nurses have lack of understanding of EB.
- Lack of recognition of EB Simplex.
- A&E - training staff on EB.
- Knowledge needed on following up after treatments and hospital visits.

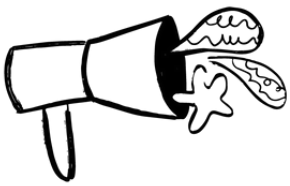
Access to information

- Information on new dressings.
- [How to go about] contacting doctors/services.
- Finding out about new treatment options.

EB awareness in society

- EB travel card [particularly for airports].
- Raise Debra's voice so that EB is more widely recognised.

Advocacy



Group Two - Gaps in current services/supports

Mental health

- Mental health supports / mental health care.
- Counselling and mental health support for teenagers in the community, but maybe not labelling it 'mental health'.
- Teenagers getting to do fun things - create a space for social interaction.

Access to medical professionals

- [Access to] OTs.
- [Access to] dentistry.
- Foot workshop with samples of socks, creams, advice and information on how to care for feet (for teenagers).
- A podiatrist or physiotherapist with EB knowledge regarding feet in the community.

EB awareness in society

- Awareness top down in schools (no repetition each year).
- Local awareness.

Access to resources

- Nursing help when needed.
- School supplies (e.g. iPads).
- Disabled parking.
- [There is a] postcode lottery.
- More help in rural Ireland.
- Pretty covers for over bandages.
- Access to dressings/ hard to get bandages/ provision of bandages and creams.
- Financial supports for EB activities (e.g. sports).

Access to information

- Sharing what others do [to manage] challenges.
- Family planning.
- Sports awareness/ education.

Medical staff capacity and knowledge

- Lack of awareness among medical professionals.
- Need more information for doctors.
- Follow-up after consultation.

Advocacy task conclusion

The facilitators shared the gaps identified by their group with the panel. A number of overarching themes emerged identifying gaps across care in the community and hospital, mental health supports, access to important medical and social resources, and the need for better understanding and awareness of EB.

Joanna closed this discussion, thanking the panel for participating. She explained that the gaps they identified will be fed into the development of the Butterfly Review and will be shared with the project advisory group. She also explained that there will be more opportunities for people to participate in the project once it gets underway.

Closing Remarks

Sinéad Hickey - Head of Research

Sinéad thanked everyone for attending the second workshop and said she hoped they enjoyed themselves and that they would continue to engage with the team as EB Experts. She then explained the plan going forward is to hold another workshop in September/October this year, and to approach the panellists individually for smaller tasks between workshops. The frequency of individual tasks will depend on the Debra team's needs as well as on the availability of the EB Experts. Most of these sort of tasks should not take up a lot of time and the majority of them will be remote and will not require travel.

All input provided will be invaluable to the team so Sinéad emphasised how grateful the Advocacy, Family Support and Research teams are for everyone's participation. She also reminded the panel that being an EB Expert did not mean they have to say yes to every opportunity that arises and that the Debra team totally understand if they cannot participate in everything that is asked of them. She reminded the panel that for anything they do say 'yes' to, they will be fully supported by either herself, Kate, Sarah, Eve or Joanna.

Sinéad then asked members to fill out a feedback form related to the workshop, which will allow the team to make improvements to these events going forward.

Further Information

For further information on the EB Expert Panel or any information within this report, please contact Sarah:

E: sarah.mullins@debra.ie

Pictured: EB Experts, Researchers and Debra Staff Members who attended the EB Expert Workshop May 2023

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