Interviews

In this interview series, EMJ speaks with leading voices in dermatology, exploring advances in epidermolysis bullosa, hidradenitis suppurativa, melanoma, and dermatoscopy. Across rare disease care, personalised treatment, early diagnosis, clinical trials, patient involvement, imaging, AI, and emerging therapies, they examine how innovation and collaboration are reshaping dermatological practice and improving outcomes.

Featuring: Sagair Hussain, Eva Vilarrasa, Ketty Peris, and Harald Kittler



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Q1 For readers who may be less familiar with epidermolysis bullosa (EB), could you briefly explain the disease, its underlying pathogenesis, and how it presents clinically?

EB is a group of rare inherited genetic skin conditions characterised by extreme fragility of the skin and mucosal surfaces. Even minor friction can cause trauma that can lead to blistering or wounds.

At the biological level, EB is caused by faulty or mutated genes. One of the challenges with EB is that it's caused by 30 different types of genes. That can give rise to four main types of EB: EB simplex, which accounts for 70% of cases; dystrophic EB, which accounts for 25%; junctional EB; which accounts for 5%; and then Kindler EB, which is very rare. What is common amongst all of them, however, is pain, blisters, itch, and the need for frequent wound care.

Clinically, EB presents at different times. The less severe forms of EB can present later on, around 6 months of age or during the toddler years, whereas at the severe end, there can be children born with 6% of their skin missing.

The more severe the EB is, the more chronic the wounds and scarring, and unfortunately, in some cases, the person is predisposed to getting skin cancer. It is a complex multi-system condition. We spoke just about the skin, but it actually impacts internal organs, as well as the eyes and mouth.

Q2 EB management has changed considerably in recent years. What do you see as the most important advances in patient care over the past 5–10 years?

I think there's been a big change. Before, it used to be supportive care because there weren't any treatments available. However, in the last 5 years, we've seen a huge change. We've got much better

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wound management and pain control, and we're much better at preventing complications. There have been significant changes in care, particularly around nutrition, infection, cancer surveillance, and psychological support, because we know that it doesn't just impact that individual; it impacts the entire family. There is now more of a holistic view on managing the condition, not just the individual. Because, ultimately, what we want is improved quality of life. Survival alone is not enough: good quality of life is vital too.



The most recent and biggest breakthroughs have been in therapies. We had the first treatment approved for EB 2 years ago in the UK (birch triterpenes), and in the USA, you can see the gene therapy beremagene geperpavec has been approved. So, it's been huge. The field is going from being quite reactive to being proactive in terms of care. And that's been the biggest shift.

Q3 As you mentioned, we have seen encouraging progress in gene, cell, and protein-based therapies for EB. Which emerging therapeutic approaches are generating the greatest excitement among researchers and clinicians?

In the UK, we've only got one treatment that's approved for EB, and that's a topical birch bark extract anti-inflammatory gel, but we are very pleased to at least have one approved drug treatment. We've had some patients who have reported that some of their chronic wounds have now closed up after being open for many years. That's been a huge difference that we have seen in the impact that it has. If you look across the Atlantic Ocean to the USA, I think that's where the biggest shift has been. Not three treatments approved. They have beremagene geperpavec, which is a topical gene therapy for recessive dystrophic EB and dominant dystrophic EB; prademagene zamikeracel, which is an autologous gene skin graft done using the patient's own cells; and allogeneic skin-derived ABCB5-positive mesenchymal stem cells, another cell-based therapy. There are other treatments like diacerein, which is for EB simplex.

I think it's a really exciting time. If you look across the treatment pipeline, there are protein therapies coming through as well. From DEBRA's point of view, our focus is on securing repurposed drug therapies for EB, primarily repurposing existing anti-inflammatory biologics so that they can treat the symptoms of EB too.

Early indications from the dupilumab clinical trial that we are funding show significant improvements to wound healing, which could make a massive difference to quality of life. Currently, we're funding three drug repurposing projects. One is looking at apremilast for EB simplex in France. We're also supporting Amy Paller at Northwestern University, Illinois, USA. And we've just launched the ART-EB project, led by Su Lwin at King's College London, UK, which is the biggest drug repurposing platform for EB.

Q4 How do you see the treatment and management of EB changing over the next 5–10 years?

I think the big change is going to be co-therapy treatments. Now, especially in the UK, we've got a single approved treatment for EB, and it is still the best option we have. But, going forward, as more treatments get approved, I think we will get to see a lot more co-therapies.

We should take a more proactive approach to treating wounds rather than a reactive approach. Hopefully, we'll also be able to intervene much earlier in children. If we can treat children early enough, in that key window, we can change the trajectory of the condition. By the time the patient reaches adulthood, a lot of the damage is already done. But for us to know if early intervention is effective, we need data, and that is where AI fits in.

Going forward, I think there needs to be a lot more collaboration

because the ecosystem is quite fragmented, not just from a research point of view, but also from a funding, regulatory, and policy point of view. The ambition is there, no doubt about it. It's really about collaboration. Once we get that data and natural history in there, that's where AI can help. What the field needs is to have data-driven conversations so we can make data-driven decisions.

Q6 Translating promising research into clinical practice is often a lengthy process. What are the main barriers to moving EB innovations from the laboratory into routine care and healthcare policy?

There are lots of different barriers, but the key barrier is fragmentation: data, research funding for EB, and regulatory approaches are fragmented. So, how do we approve drugs?

> **There are 30 different types of EB caused by 30 different genes, which means we cannot have a one-size-fits-all approach**

Q5 What are the biggest scientific and clinical challenges that still stand in the way of developing curative therapies for EB?

I think the biggest challenge is just the complexity of EB. EB is not a single monogenic condition. There are 30 different types of EB caused by 30 different genes, which means we cannot have a one-size-fits-all approach.

There isn't going to be one magic tablet that cures or treats everybody with EB. We need to develop different treatments for the different EB types, and to do that, we need to understand the mechanism and how the disease progresses. That's going to be the biggest challenge.

How EB simplex progresses over time is going to be vastly different to how dystrophic EB progresses. So, it's about understanding disease progression and natural history: ultimately, it comes back to data. I think data is going to be the key for us.

The way treatments are approved in the UK is very different from how they're approved in the USA or in other countries. And that adds to the complexity. Clinical infrastructure in some centres in some countries is better set up for clinical trials than others.

This makes it really hard to collect the robust and consistent evidence needed for regulatory approval, because regulatory approval is the last hurdle. If we can't get over this last step, we can't get these treatments to the patients who desperately need them.

Another challenge is the trial design. It's a rare condition, so do we have enough patients to recruit for a trial? And even if there is a therapy, there's the manufacturing challenge of producing it at a scale that's cost effective for development. We must try to address all these barriers to get to the regulator. What we need is more alignment between academia, industry, regulators, and patient organisations. Because, fundamentally, it comes down to the patients. We want to get the treatments to our patients, and doing so requires more and better collaboration.

Q7 Clinical trials in rare diseases present unique challenges. What lessons has the EB community learned about trial design, recruitment, and meaningful outcome measures?

One of the most important lessons is that trial designs must be about the patients and can't just be about the science. The endpoints that you collect must be meaningful to the patients, not just from a scientific point of view. They must address pain, itch, inflammation, and wound management, the symptoms that have the greatest impact on quality of life for people living with EB today.

It's that endpoint that measures the changing quality of life, rather than relying on those traditional clinical measures. The thing that we've learned is that coordination is essential. Being a rare condition and having a small population, we need to work together and have multicentred clinical trials, because it's hard for a single centre or a single country to recruit enough patients. One of the biggest failures with clinical trials is not having enough patients recruited; that's what we need to change.

Another thing is that patient recruitment needs to fit around the patients. There's no point in having a clinical trial centre that is 2,300 miles away from the patient. We need to check, from a practical point of view, how the patient gets to the centre. We need to fit it around the patients because if we don't, we will lose the patients in the trial, and eventually the trial will fail, not because it wasn't good, but because we couldn't recruit patients.

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I think that's the biggest shift: to make sure that patients' needs are at the centre of the trial design.

Q8 How important is patient involvement in shaping the research agenda, and how has DEBRA incorporated the patient voice into its research strategy?

DEBRA is a membership organisation, and many of our members are patients with EB. They are the heart of everything we do, from top down or bottom up. If you look at our trustees, over 50% of them either have EB themselves or have a close family link to someone with EB. What that means is we don't lose that patient voice. If you look at our committee structure, we always have a patient voice present. From a research point of view, they are at the heart of research because, fundamentally, we want to improve their quality of life. So, they're fully embedded in the research process.

Last year, we completed the James Lind Alliance (JLA) Priority Setting Partnership to understand the unmet need and identify the top 10 research priorities for all EB types. We did this globally, not just at the UK level. It was the first time a global JLA partnership had been carried out for such a complex and rare condition.

We also won an award because it was such an innovative way of doing it. This work will guide us for the coming years, ensuring we fund research projects that best meet the needs of the EB community.

On top of that, most researchers, especially basic scientists, have never met a patient, and I'm one of them. I did a PhD, three post-docs, and worked for 15 years in the lab, never meeting a single patient. So, what we set up is these abstract clinics, where we get the researchers to meet the patients and the researchers have an opportunity to pitch their idea to the patients.

When we receive applications, we have a lived experience panel who review the application, not on a scientific level, because they're not science experts, but they are are EB experts. They're looking at questions like: does the idea in this application address a patient's challenge? We understand that not all projects do that. For example, in mechanistic projects, we just understand EB; that's not a patient.

So, it's about finding the right balance. Having that patient input there is important and, going forward, patients will be a priority; they will have input every single step of the way.

Q9 If you could change one thing about the current EB research and care landscape tomorrow, what would it be?

I think it's probably the lack of alignment across the field. There's definitely no shortage of ambition and innovation in EB research. I think the progress is slowed down by fragmentation of data, strategy, and lack of funding. We need to bring these elements together through research projects or shared priorities, coordinating infrastructure, opening up more collaboration, and having multicentred clinical trials. This would make a significant difference. Ultimately, if we can align all of these, not just the discovery, we can get faster and better treatments for patients with EB. Because ultimately, it's about the patients with EB and making notable improvements to their quality of life.



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