

How Community Support and Healthcare has made a huge difference to us

When their son was diagnosed with EB, DEBRA's Community Support team and the specialist Healthcare team at Birmingham Children's Hospital helped new parents Hayee and Sidra get the support they needed.

“**Knowing Rafay is getting the best support gives us peace of mind**”

My wife and I had never heard of EB before our son Rafay was born. Now it's at the centre of our lives.

Luckily, Rafay was born in Manchester General Hospital, diagnosed with Recessive Dystrophic EB and referred to the specialist EB Healthcare team at Birmingham Children's Hospital shortly after birth. But understanding what EB would mean for us wasn't easy. At the time, we'd only been living in the UK for about six months and English is not our first language – we come from Pakistan originally, where Urdu and Punjabi are spoken at home. It was completely overwhelming, trying to understand complex medical terms and learn how to look after Rafay, change his dressings and protect his skin. Thankfully, our DEBRA EB community support manager and our specialist EB nurse were able to help us.

Zainib Hussain, our DEBRA EB community support manager and Victoria Warren, our specialist EB nurse, work closely together to help us convey any concerns we have. Zainib has even attended home visits with Victoria where she has been able to translate for us if needed. People often have to face so many difficulties in life. Thanks to Zainib, one of those difficulties – the language barrier – has been lifted.

Victoria has been wonderful too, going beyond the call of duty to make sure Rafay gets the care he needs. We had some difficulty obtaining the right dressings for Rafay on prescription. Victoria spent a lot of time on the phone explaining EB to our GP and even visited the surgery in person to make sure they really understood Rafay's needs and could provide appropriate dressings and medications.

We're glad to have her dedication – Rafay's our beautiful baby, our first born son, but it's frightening having a child with a very rare condition like EB. Since he was born, he has had to stay in hospital several times, has had infections all over his body, and at times he has had blisters in his mouth and been unable to feed. We will always worry, but knowing he is getting the best possible care and support gives us peace of mind.



Smiling: Rafay with his dad Hayee.

While the Healthcare team has been on hand to help us deal with Rafay's medical needs, the DEBRA EB Community Support team has enabled us to understand and navigate the complex and confusing world of health and social care systems. Zainib has helped us with our applications for Tax Credits and Disability Living Allowance (DLA) for Rafay, as well as signposting us to other organisations for support with other things, like immigration issues. We've also received a support grant from DEBRA to purchase essential items for Rafay.

“**Now my priority is my child... I don't think about myself**”

Now, when we need support, we always contact Zainib who is just a phone call away. We've received a lot of support from DEBRA in many ways – I honestly don't know how we'd manage without them.

Hayee Abdul

DEBRA funds 10% of the salary of each EB Clinical Nurse Specialist in the team at Birmingham Children's Hospital, enabling them to offer an enhanced healthcare service to people living with EB. Find out more at www.debra.org.uk/nhspartnership.