

A new era of partnership working: DEBRA and the NHS



HRH Countess of Wessex visit to epidermolysis bullosa clinic

Twenty-nine years ago DEBRA made history by funding the world's first epidermolysis bullosa (EB) specialist nurse. This service grew into the EB nursing service, which was for many years solely funded by DEBRA. This changed in December 2011, when the charity successfully lobbied to receive full funding for all care that the NHS has a duty to provide, along with a clear charter of what patients can expect from the NHS and DEBRA. DEBRA, the NHS commissioners, clinical teams and managers worked together to review and further develop the specialist EB medical and non-medical support services, and from this, a new era of partnership working commenced with the NHS funding core activities and DEBRA funding enhanced, non-core activities, e.g. additional bereavement visits, assistance with research nursing and outreach services. All EB nurses were subsequently given primary NHS contracts under the NHS regulatory umbrella, which brought a host of benefits including access to all health records/blood results, and enhanced training and development opportunities. The NHS also offered honorary contracts to the DEBRA community support managers, enabling them to work closely with the clinical teams and attend clinics.

The partnership came at a time of government cuts and reductions in NHS budgets, so it was a remarkable outcome for everyone living and working with EB and has since paved the way for a unified and consistent approach to service delivery, management and access. Dual organisational funding has not only enhanced stability — it has given patients living with EB access to holistic care and support. The partnership, which represented significant savings to DEBRA, has also allowed the charity to commit to further develop the non-medical support service, including additional funding for occupational therapy, podiatry, dieticians, outreach multidisciplinary team (MDT) clinics and a specialist EB clinical fellow post; training and clinical supervision opportunities; expansion of the community support team to meet the increasing demands of the EB community (particularly following welfare reforms); development of clinical best practice guidelines to improve knowledge and understanding internationally; and an increase in the number of

DEBRA holiday homes to offer more families much-needed respite.

A UNIQUE SERVICE

The MDT approach to medical and non-medical EB support, essential to people living with such a complex condition, continues to develop; DEBRA is very proud to have funded the first EB specialist nurse and continues to part-fund them today, as well as other specialist services (the services and level of funding vary between hospitals) including podiatrists, dietitians and occupational therapists. The EB Healthcare Service, which is one of only two highly specialised/commissioned rare condition dermatology services in the UK (NHS England, 2016) and is an internationally respected flagship service, is delivered across four EB Centres of Excellence:

- ▶ Great Ormond Street Children's Hospital
- ▶ Guy's and St. Thomas' NHS Foundation Trust
- ▶ Birmingham Children's Hospital
- ▶ Solihull Hospital.

All centres are nationally commissioned by the NHS specialist national commissioning team and are staffed by highly specialised MDTs, including consultant dermatologists, plastic surgeons, dentists, hand therapists, podiatrists, dietitians and psychologists. All four centres maintain a close working partnership with the DEBRA community support team and work closely together to provide specialised care to the EB community. The teams also carry out essential medical and clinical research and have helped establish specialised clinics, outreach support and regional services across England and Scotland.

The partnership between DEBRA and the NHS has been a huge success — not only because it prevents a fragmented service and enhances efficiency, but because it improves the quality of life of children and adults who are living with this terrible condition. *"Having access to an expert multidisciplinary team is invaluable. I know I'm in safe hands – my care is well informed and the team always has access to the most up-to-date knowledge on EB. My medical care, as well as the non-medical support, that I need is joined up, it's less stressful and works really well."* Scott O'Sullivan, DEBRA Trustee and patient with EB.



REFERENCES

NHS England (2016) *Specialised Dermatology*. Available at: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a12/> (accessed 07.04.2016)

Further information

If you would like more information on DEBRA or EB, or if you are interested in attending a course or study day, please visit: www.debra.org.uk/healthcare-professionals

