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Banking on Change at Hearts

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By Gillian Weaver

Author Gillian Weaver has spent almost three decades immersed in the connected worlds of breastfeeding support and human milk banking. Together with Epigeneticist[1] and former Paediatric Surgeon Dr Natalie Shenker, she is now working to bring a change of approach to the provision of donor breastmilk and to lactation support. They co-founded the Hearts Milk Bank in 2016 which became fully operational in June 2017. They also recently launched the Human Milk Foundation, a charity that will help to support the work of human milk banks as together they expand assured availability of donor human milk geographically and to babies who previously would not have had access to donated human milk.

Milk Banks: A History

Human milk banks were introduced to the UK almost 80 years ago. The first was located at Queen Charlotte's Hospital in West London and officially opened in 1939. Others started to open throughout the UK after the 2nd World War and the numbers grew throughout the 1950s and 60s. The milk was collected from donors at home and the milk was heat treated and frozen in rudimentary freezers or used within 24 hours. Hospital based, less formal milk sharing operations began to take over and many mothers from the 70s and 80s who were resident in the postnatal wards will recall being asked to express milk for babies whose mothers didn't have enough, especially for babies on the neonatal unit and for twins and triplets. The milk was often used without any treatment but in many instances it was simply boiled in a saucepan in the ward kitchen.

However, change was afoot! Guidelines published by the then Department of Health and Social Security in 1981[2] recommended bacteriological screening and heat treatment of breastmilk, and the 1980s saw an end to the payment of paltry sums to the mothers who provided the milk. Purely altruistic donation became the norm and 'donor human milk' or 'donor milk' for short has since replaced the commonly used term 'bank milk'. The introduction of mandatory and more sophisticated heat treatments and extensive screening of donors also has its roots in the 80s as part of the aftermath of the global rise of HIV infection [3]. The development and marketing of specialist preterm infant formula milks and financial cuts across the NHS combined with concerns about risks of HIV transmission almost killed off milk banks across the UK as well as globally. Subsequently, however, published evidence of lower rates of necrotizing enterocolitis in preterm infants fed only human milk, including exclusively donor human milk, became available in the early 1990s[4]. This led to the overall numbers of milk banks increasing again including in the UK, with 17 fully operational by 2007. The publication of national guidelines in the 90s[5], followed by the NICE clinical guideline 93[6] in 2010, have standardized UK milk banking practices and led to greater quality assurance and improved traceability.

During the 1990s and into the new millennium there was renewed investment in milk banks; new ones were established and those that had survived the 80s decline, started to grow and expand their provision to include additional hospitals[7]. Donor recruitment, volumes of milk collected and processed and the provision of donor milk all increased year on year throughout the 90s and 2000s. However, current financial constraints within the NHS have impacted negatively on some milk banks and much needed investment has not been widely available. This has compromised the use of donor milk especially as, even for preterm infants, its use is not without critics within neonatal circles. The endorsement of national guidelines by the British Paediatric Association (BPA)[5] and then by the Royal College of Paediatrics and Child Health (RCPCH)[5], followed by the publication of the National Institute of Health and Care Excellence (NICE) Guideline CG93[6], addressed safety concerns but questions were raised in the UK about the value of donor milk, about its cost effectiveness and the usefulness of human milk banks. Despite the growing body of evidence about the positive role of milk banks and donor milk (when used appropriately) in supporting lactation and breastfeeding the opposite has often been cited[9]! In addition, doubts about the evidence base with regard to donor milk and necrotizing enterocolitis have bedeviled milk banking for two decades now. Sadly research that had sufficient numbers of babies in it to get a clear

result and that addresses the feeding regimes appropriate to UK preterm nutrition has remained elusive. Planned multi-centre trials may still take place, however many neonatal feeding specialists are reluctant to randomise infants to a diet that may leave them without any or little human milk if the mother struggles with establishing her milk supply. Study designs that take account of this are a possibility, but funding for a very large trial has not yet been found.

On the other hand, the recognised benefits of donor milk compared to infant formula are fewer babies contracting sepsis and necrotizing enterocolitis, better feed tolerance and shorter hospital stay, and are unsurprising given the known contents of human milk and the good retention rates of immune components after the pasteurisation process.[8]

The use of donor milk as part of routine neonatal unit infant feeding protocols is associated with increased breastfeeding rates on discharge[9] as well as overall volumes of breastmilk intake[10]. Milk banking and donor milk proponents have long advocated its appropriate use as part of overall lactation support. They have similarly cautioned against using donor milk without also supporting women to express their own colostrum[7] (preferably within the first hour but at least within the first six hours) and without on going support for mothers to provide their own milk. When supplementing babies whose mothers are temporarily unable to provide enough of their own milk, the availability and use of donor milk is known to be interpreted by mothers as providing a bridge to breastfeeding and not, as the use of formula is perceived, as an end to it[11].

Improvements to Scotland's only milk bank had been supported by the Scottish government. Charitable funding had helped to develop a new facility in Glasgow and this enabled the development of a nationwide service in Scotland in 2013[12]. Donor milk supplies to neonatal units are now funded by the regional health boards of Scotland and a recent boost in funds from the Scottish government will enable more infants in hospital to receive breastmilk. The development of regional services has also made headway in the South West of England where the Bristol based Precious Drops Milk Bank received financial support from NHS England to increase provision of milk to neonatal units in Cornwall, Devon and Somerset as well as in Avon. The North West Mother's Milk Bank, formed after the amalgamation of the Wirral Mothers' Milk Bank and the Cheshire and North Wales Milk Bank, has grown year on year and continues to supply donor milk across the north of England and further afield if local milk banks are unable to meet demand. Their establishment of a number of depots in the north of England has enabled neonatal units to rapidly access milk when needed. However, elsewhere in England, local hospital based milk banks were often unable to fulfill local need. This was especially the case in London and the South East where suddenly milk banks were providing less milk to external Trusts, and assured supplies were becoming more difficult for neonatal units to obtain. It was not unusual for nursing staff to be spending several hours trying to locate supplies of donor milk and there were even examples of them having to take taxis across London to access small amounts of milk. Without assured access, the use of donor milk began to decline in the south east, and hospitals that had been planning to introduce it to neonatal feeding protocols had to place their plans on hold.

The Hearts Milk Bank

It was against this backdrop that the Hearts Milk Bank (HMB – www.heartsmilkbank.org) was founded in March 2016. It is a community interest company (CIC) that operates on a not for profit basis and was founded with the intention of bridging the gap in provision of donor milk throughout London and the South East. It is the first independent milk bank to be founded in the UK and received no NHS or government funding. The Hearts Milk Bank has three aims, and the second two are what makes it stand out from other UK milk banks:

1. The main aim of the Hearts Milk Bank is to provide safe and assured supplies of donor milk to any hospital neonatal or paediatric unit that is unable to access it from local hospital based milk banks.

2. A secondary aim is to promote and support human milk based research particularly into epigenetic studies of breast cancer but also in ethically approved areas of human milk and infant feeding. Areas for further research highlighted in both the NICE guideline[6] in 2010 and the BAPM report[12] in 2016 have not yet been addressed in the UK and the Hearts Milk Bank aims to facilitate these and other studies.

3. The provision of safe, screened donor milk to mothers whose babies are not premature or unwell, which, when combined with high quality IBCLC-led support ensures that women who do not wish to use formula, but (short or long term) need extra milk, can access human milk instead.

Support and mentorship from the University of Cambridge's Judge Business School and being awarded a very prestigious Mass Challenge prize in 2017, together with other business accolades, provided much needed reassurance that this was a sustainable and forward thinking model for human milk banking. Crowd funding and financial donations enabled the Human Milk Bank to start. The milk bank's proximity to local Hertfordshire and Bedfordshire SERV (Service by Emergency Rider Volunteers) provides a very important bonus as their volunteer motorcyclists are an indispensible part of the overall operation. The Blood Bikes, as they are known colloquially, have revolutionized human milk banking in the UK by providing not only free milk collection and delivery services but by being able to coordinate these in a way that frees up time for the milk bank administrative staff.

In addition to the co-founders, the milk bank benefits from staff with International Board Certified Lactation Consultants (IBCLCs), midwifery and hospital infant feeding specialist expertise and from pharmacy technician and breastfeeding support experience as well as from the expert advice panel that includes leaders in the fields of clinical microbiology, neonatology and breastmilk related pharmacology. A small group of greatly appreciated volunteers lend a hand with some of the administration and with marketing and promotion.

In the first 15 months of operation the Hearts Milk Bank has supplied milk to 27 hospitals with half of these unable to previously use donor milk due to a lack of assured access. More hospital neonatal units expect to introduce donor milk into their feeding protocols in the coming months. The bank has recruited over 200 donors and is currently providing over 100 litres of milk a month to both hospital and community infants.

Donor milk for babies who are not unwell

The provision of donor milk to babies at home came about as the result of having an ongoing surplus of milk, no shortage of mothers offering to become donors and increasing requests for milk from mothers unable or struggling to lactate. This led to the decision to provide donor milk, when available, to community based infants in circumstances where the request came via a health care professional and where the provision of donor milk wouldn't undermine the baby's chances of receiving their mother's own milk. These include where the baby's mother has received an antenatal cancer diagnosis, has previously undergone bilateral mastectomy surgery, is taking medication absolutely contraindicated for breastfeeding (eg antipsychotic drugs) or is HIV positive and advised not to breastfeed. In all of these cases the donor milk is provided with the mother's health and wellbeing in mind in addition to the benefits of providing human milk for the infant. A final group of infants for whom in the future donor milk will become increasingly available via the Human Milk Bank are those who need a temporary supplementation whilst the mother's lactation improves and/or breastfeeding becomes established. It is envisaged that when used with the help of qualified and experienced breastfeeding supporters, the provision of a few feeds of donor milk will avoid the use of cow's milk formula and support the development of or return to full maternal milk feeds.

The Human Milk Foundation

The most recent news from the HMB is that the co-founders have collaborated with experts in the fields of cancer research and fund raising to create a new UK charity - the Human Milk Foundation (www.humanmilkfoundation.org). This has been established to support parents, facilitate increased supplies of milk to families who otherwise would not have access to human milk for their infants, to promote education around human milk and to promote and support research into human milk.

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