PE1426/M

PE 01426 National Donor Milk Bank Service

Petitioner Response to NHS GGC letter dated 24th April 2013

I am delighted to hear that a national donor milk bank service for Scotland has been developed and is due to be launched shortly. That the health authorities of Scotland have managed to orchestrate this is testament not only to the huge efforts of the health care professionals and volunteers involved but also to the growing recognition of the importance of donor breast milk for vulnerable premature babies when their own mother's milk is in short supply or unavailable.

However, a number of points made by NHS GGC bear closer consideration. I lodged this petition to address the inequality of access to donor breast milk across Scotland. The statement that "some neonatal units will not be proactively offering donor milk to infants who meet the clinical criteria" does not suggest that this original problem has been fully resolved. A preterm baby and their parents have the right to an equal standard of treatment anywhere in Scotland, regardless of the health authority. If some units are "proactively" offering donor milk but others are not, this will create a disparity that has important ethical implications.

It is also hugely concerning to read in the appendix that two health authorities (Forth Valley and Orkney) have "declined to participate" and a third (Shetland) have not responded to emails they have received and read on this issue, let alone made a formal decision to opt in or out. Although the Glasgow milk bank has provided donor milk to other Health Boards "on request as available"², this will cease when the new national service launches. It will presumably be unworkable for Glasgow to continue dispensing milk on request after June if the recipient health authority has not paid for their share of the service. It would arguably be grossly unfair to the health authorities who have paid their proportional share if exceptions are made as this would create a contentious 'free rider' problem.

In the case of Forth Valley, which is a health authority that provides tertiary level neonatal care, this would mean that their clinicians will be unable to access donor breast milk from the Glasgow milk bank. Forth Valley's lack of participation in the service has left a large shortfall in the funding of almost £9000 and this will mean that babies in clinical need from that area could be denied access to an important and potentially life-saving resource. Equally, this could raise huge ethical issues for clinicians in other health authorities who wish to use donor milk for babies from Forth Valley who have been transferred to them for more specialised care because the milk has, in practice, not been paid for. In addition, the costs of screening breast

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http://www.scottish.parliament.uk/S4_PublicPetitionsCommittee/General%20Documents/PE1426_L_NHS_Greater_Glasgow_and_Clyde_24.04.13.pdf Section 5.3, page 3.

²http://www.scottish.parliament.uk/S4_PublicPetitionsCommittee/General%20Documents/PE1426_L_NHS_Gr eater Glasgow and Clyde 24.04.13.pdf Section 4.2. page 2.

milk donors from Forth Valley would also not have been covered so donation from these potential volunteers could not be pursued.

Clearly, no-one would wish to see these scenarios happening in a Scottish neonatal unit. Prior to the launch of the 2011 pilot scheme, a preterm infant born in Glasgow with access to the donor milk service had a 60% greater chance of survival than an infant with identical clinical needs born only a few miles away in Lanarkshire who did not³, therefore the medical implications of Forth Valley's lack of participation are considerable. In the case of Orkney and Shetland, although donor breast milk would not be used on the islands themselves as preterm babies are routinely transferred to the mainland, the same principles would apply as without each of these contributions (£694 and £793 respectively), any donor milk required for any babies who belong to these authorities would also not have been paid for.

It is particularly disappointing to note that these three boards have not opted in to the national milk bank service because even in this difficult financial climate the rest are fully behind this initiative and have found or are in the process of finding the money to pay their share. The national milk bank will be a first for Scotland and the UK and it seems very short-sighted to fail to play a part in something so revolutionary that will deliver very real benefits to vulnerable babies. Any concerns over finances should be measured against the observation made by NHS GGC the last time the petition was raised that even just one less case of NEC a year in Scotland (a condition that is dose-responsive to a lack of human milk feeding in preterm babies) would fully fund the national donor milk bank service for the whole country.

Donna Scott 28th April 2013

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³ http://giveacar.co.uk/charities/scotservs-scottish-emergency-rider-volunteer-service