PE1426/A

NHS Greater Glasgow and Clyde's response to the Public petition *18/5/*12 requesting equitable Donor Milk Bank provision across Scotland

1. What is your response to what the petition seeks?

NHS Greater Glasgow and Clyde (GGC) will continue to provide a Donor Milk Bank service for the use of its most vulnerable infants admitted to neonatal services. GGC acknowledges that the provision of donor breast milk is inequitable across Scotland and recognises that the demand for donor milk is increasing and is likely to escalate further.

a. Clinical Evidence; Despite the best available support and equipment some mothers will have a physiological difficulty establishing lactation; particularly those who give birth before 32 weeks gestation. There is an evidence base and growing clinical enthusiasm for the use of donor breast milk reflected in the recent, American Academy of Paediatric Policy Statement; Breastfeeding and the Use of Human Milk (February 2012) which states;

"*The potent benefits of human milk are such that all preterm infants should receive human milk. If mother's own milk is unavailable despite significant lactation support, pasteurized donor milk should be used."* [1]

Despite huge advances in neonatal care, necrotising enterocolitis[2] [3] remains a major cause of mortality in preterm infants and is associated with significant long-term health-care costs. [4] [5] [6] [7] It is the most devastating preterm bowel condition which attracts an enormous financial burden due to the increased duration and complexity of care required. Those babies who require laparotomy, gut resection and stoma formation followed by prolonged parenteral nutrition prior to stoma closure have a median in-patient stay of 6 months. Care for these infants requires highly skilled multidisciplinary input, available only in a limited number of regional centres. In the longer term, this places a huge psychosocial burden on parents and requires ongoing nutritional support and regular hospital review over many years.

An additional burden of significant health inequalities exists amongst the most vulnerable sick and premature infants and breast milk may be even more beneficial for this group.[8] Studies of neuro-developmental outcomes indicate a larger deficit in low birth weight infants not receiving breast milk[9] and vulnerable infants fed with enriched formula milk may have up to 28% more body fat raising concerns about an increased risk of future metabolic disease.[10]

b. Wider Awareness; The UNICEF UK Baby Friendly Initiative have been modernising their standards and these are available for wide consultation. The new document includes neonatal standards and promotes the use of breast milk[11]. The Charity, "*Best Beginnings*" has produced a DVD (*Small Wonders)* for parents of premature and sick infants and it will be distributed routinely. Donor milk is discussed in the DVD. Infants and medical staff often move between units and may access milk from the GGC Donor Milk Bank service. There an increasing variety of routes that lead parents and professionals to a greater awareness of the potential benefits of donor milk.

2. The Committee would be interested to hear of your experiences and of what work that you do in relation to the donor milk service that you provide.

The donor milk bank opened in 1978 at the Queen Mother's Hospital in Glasgow and provided milk for premature babies and for more mature babies who had undergone a variety of gastrointestinal surgeries in the co-located Royal Hospital for Sick Children at Yorkhill when mothers could not produce their own milk. It had no dedicated staff at this time but only handled milk from 8 to 12 donors and 8 to 16 recipient babies annually. Since then the GGC milk bank has expanded into all maternity units in GGC.

a. Safety Standards; internationally, milk banks are well established and across the UK there are now 17 in existence but only one in Scotland. The National Institute for Clinical Excellence (N.I.C.E.) UK[12], the United Kingdom Association for Milk Banking (UKAMB) and the Human Milk Banking Association of North America have all published guidelines for the establishment and operation of human milk banks. The GGC milk bank has a management team which includes input from Scottish National Blood Transfusion Service (SNBTS). It has overseen the milk bank upgrade process and is responsible for implementing and auditing standards

b. Expansion; The service has developed and expanded significantly in the last 3 years; both in the processing of donor milk and the numbers of babies who receive milk. The existing bank has never had specific funding. CEL 36 funds to support HEAT target 7 was used to upgrade the service and ensure equity across GGC and this has now been fully achieved. Considerable funding towards equipment (freezers and pasteurisers) and development of the new milk management system was provided from Yorkhill Children‟s Foundation and endowment funds.

In 2010, 38% of the milk donors lived out with GGC, increasing to 40.6% in 2011 and 53.3% so far in 2012. Over the last year a similar increase in the percentage of milk being used in Neonatal Units outside GGC has been seen (so far in 2012; 17%). Each year, from 2008, the number of donors, the amount of milk and the number of recipients has been increasing; in 2008 35 donors produced 102.8 litres of milk and fed 32 babies and by 2011 64 donors produced 427.35 litres and fed 104 babies.

c. Processing milk; In accordance with the 2010 NICE Guideline, all donors are rigorously screened in conjunction with SNBTS who carry out the virology testing. All milk is heat-treated and subjected to strict bacteriological quality testing and processing regulations. This is managed by the Milk Bank Coordinator and in conjunction with SNBTS, they have developed a new milk management system, including tracking and labelling to ensure donor to recipient traceability with multiple gateways to guarantee safety at all points. Added functionality allows for stock control and a report production.

d. Milk transport; The Scottish Emergency Rider Volunteer Service (ScotsERVS) now supports the Donor Milk Bank by transporting milk to requesting units and collecting milk from donors‟ homes. Start up and petrol costs were funded by a charity donation.

3. The committee would also be interested to hear your thoughts on the potential for expanding the service that you currently offer and whether you had assessed how much this would cost to do this?

GGC Donor Milk Bank has to date met the increasing demands for donor milk. However, requests are becoming more common place and the ability to meet increased demand is not feasible without further investment.

a. Improved national infrastructure; A nationally funded service could support SNBTS to provide a Scotland wide screening process. ScotsERVS now provides a local, sustainable service across GGC and into neighbouring health boards. This volunteer provision has the potential to expand throughout Scotland. In recent weeks they have transported milk to the furthest away Neonatal Units in Scotland in Inverness and Aberdeen. Thanks to a quick response time; from request to delivery the milk arrived in less than 4 hours and it was still frozen.

b. Service development; recently, donor milk has been used in the pre and postoperative management of babies with cardiac conditions who are recognised to be at increased risk of necrotising enterocolitis. GGC has also introduced routine macronutrient analysis of breast milk and is piloting an innovative system to optimise nutritional intake for recipient babies. The milk bank is also exploring collaborative research with other UK units.

c. The Options and Cost Implications; GGC has carried out some early work to develop a business case, an options appraisal process and to estimate the costs for a national service. It has already started dialogue with other Boards and plans to continue this over 2012 and has a meeting planned in August 2012. The options are likely to include; developing a centralised National Donor Milk Bank coordinated through and run from one site only or using a linked hub and spoke (depot) model. The costs depend on the model and the number of Boards participating in the service. A very early ***estimate*** for staffing, donor screening, milk management, consumables and transport costs ranges from £157k for centralised national service to £206k for a linked hub and spoke model. However, there will be additional buildings cost to add to this and it will vary depending on the model. The current facility at Yorkhill already has costs attached but would not have the capacity to house the additional equipment required without an upgrade.

4. Summary

There is likely to be a reduction in morbidity and mortality and a potential to reduce health inequalities amongst this group of vulnerable infants exists. The evidence suggests that some cost savings associated with ready access to donor milk is possible. For every 8, extremely preterm, infants fed breast milk one less case of surgical necrotising enterocolitis is achievable[1]. It is likely that that one less case of surgical necrotising enterocolitis per year would easily fund a national Donor Milk Bank for Scotland.

GGC has achieved a safe, efficient service with a supporting infra structure and has the experience to contribute to the development of a national service. Although GGC has provided donor milk to neighbouring Health Boards on request, any further escalation of this to an equitable, national service cannot be achieved without some degree of reorganisation and further funding.

GGC recommends that a short life project board from across Scotland is convened to complete the options appraisal process, to investigate costs, to agree any additional guidelines and standard operating procedures and to manage an implementation process.

The view of GGC is that this should become a nationally funded service, with strong links to SNBTS and with a recurring budget as this would be more sustainable, equitable and efficient way to manage the service.

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