

To: Trust Chief Executives

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*For distribution to:*

- *Medical Directors*
- *Directors of Nursing*
- *AHP Leads*
- *Dietetic Heads of Service*
- *Directors of Social Care and Children's Services*

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10<sup>th</sup> March 2020

Dear Colleague,

**CHILDREN WITH COWS' MILK ALLERGY: DEVELOPMENT OF A REGIONAL MANAGEMENT PATHWAY WORKSHOP OCTOBER 2019 REPORT**

Thank you for facilitating the attendance of Trust Paediatricians, Dietitians, Health Visitors and Infant Feeding Leads to our workshop on Cows' Milk Allergy which was held in October 2019.

There was an excellent level of engagement on the day and we enclose a report which has also been shared directly with all attendees.

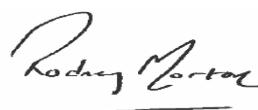
HSCB and PHA will continue to work collaboratively with Trusts and primary care to develop a regional pathway, and to progress a number of the actions that are outlined in the report. As part of this ongoing work, further engagement with stakeholders is planned and we will be in touch with you and your staff in due course around this.

In advance of this, we would appreciate it if the report could be formally disseminated to appropriate staff within your Trust, e.g. paediatricians, midwives, dietitians and health visitors, to increase awareness of the planned work in this area.

Yours sincerely,



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Assistant Director of Integrated Care  
Head of Pharmacy and Medicines  
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**Rodney Morton**  
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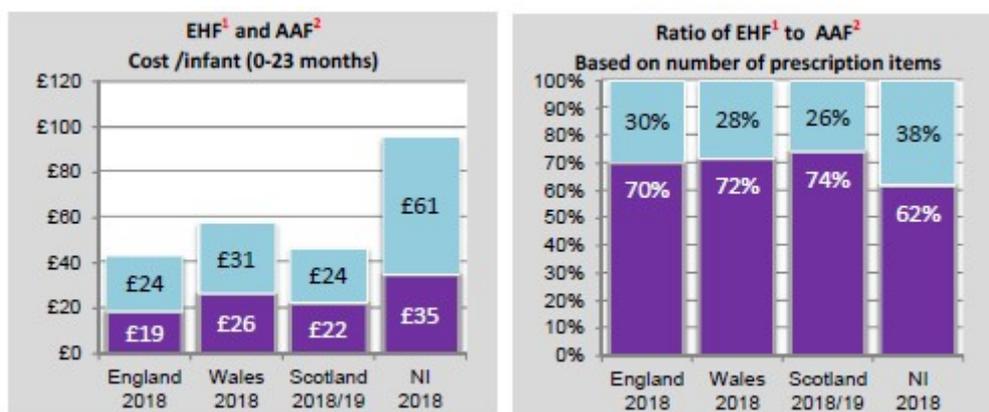
## Management of Infants with Cows' Milk Allergy Report of Regional Workshop 14<sup>th</sup> October 2019

### Background

Cow's Milk Allergy (CMA) is the most common food allergy in children. Babies with suspected CMA will present with a range of non-specific symptoms. These include pruritus, eczema, erythema, nausea, vomiting, diarrhoea, abdominal pain. The three types of CMA are IgE-mediated, Non-IgE-mediated and mixed IgE/Non-IgE, with IgE generally being more severe and having a more rapid onset (mostly within minutes of ingestion of Cows' Milk Protein – CMP)

Non-IgE-mediated CMA tends to have a less rapid onset of symptoms (within a few weeks of ingestion of CMP) and symptoms tend to be mild to moderate. CMA should be diagnosed by a suitably qualified healthcare professional.

CMA is estimated to affect 2-4% of infants in the UK, however data from the most recent Primary Care prescribing and dispensing data demonstrates that Cost/infant of formula for CMA in NI is roughly twice that of the rest of the UK (£88 in NI compared to £40, £49 and £44 in England, Wales and Scotland) In NI, during 18/19 the spend on prescriptions for infant formulae for CMA was in excess of £4.8M.



### Workshop

A HSCB/PHA organised multidisciplinary workshop was organised for October 2019 to determine how infants with suspected CMA were currently being managed across the region.

Attendees heard from Nigel Rollins, Department of Maternal, Newborn, Child and Adolescent Health and Ageing, World Health Organization, who discussed prevalence of CMA, Diagnosis of CMPA, Breastfeeding rates and the influence of the Formula Industry on prescribing rates.

Joanne McClean, PHA Consultant also spoke about rate of prescribing of CMA formula in NI and compared the volume prescribed in NI and the ratio of Extensively Hydrolysed Formula (EHF)/Amino Acid (AA) formula in NI compared to that prescribed in England. Also comparison between the different Trust areas was discussed, with a two-fold difference in the spend on CMA formula per baby born between the highest and lowest spent Trust.

A parent representative discussed her journey with CMA. She has two boys, aged 7 and 9, who are both still suffer with cows' milk allergies.

Local GP, Dr Keith McCollum, also spoke of the challenges faced by GPs when managing patients with suspected CMA and clinical system tools available to help assess and manage patients presenting with suspected CMA.

Healthcare Professionals from each Trust area were invited along to present on how infants with suspected CMA were being managed in their Trust area, these included Consultant Paediatricians, Dietitians, Health Visitors (including representatives from Sure Start groups across the region), Midwives, Infant Feeding Co-ordinators as well as GPs, Practice Based Pharmacists and Community Pharmacy representatives.

Participants were also asked to take part in a World Café session where they were encouraged to discuss various aspects of the management of CMA which included initial management, referral and review and de-prescribing of CMA formula.

Slides from the workshop can be viewed via the link below

<http://primarycare.hscni.net/download/DocLibrary/Pharmacy/Clinical/Nutrition/Infant-Nutrition/Cows-Milk-Allergy-Revising-the-Regional-Pathway-Final...pdf>

## **Summary of World Café Discussion Session**

### **1. Improving the Service**

*Based on this morning's session and your own knowledge/experience of this area, do you think there are opportunities to improve services and/or make efficiencies?*

- Education is key:
  - Antenatal education for parents on “normal” baby behaviour, expected feeding challenges, benefits of breastfeeding and links to reduced likelihood of CMA.
  - Postnatal support of feeding issues – both breast and formula.
  - Infant feeding helpline for quicker, direct access to specialist advice.
- Health Care professionals:
  - Continuity of care with HCP including seeing the same midwife/health visitor.
  - Communication between HCPs and unified approach by all HCP, including out of hours and Emergency Department staff.
  - A single set of guidelines for all to follow, tools to help with diagnosis and the same training for all staff.
- Managing parental expectations at the outset:
  - This would include early explanation of the initial trial period of CMA formula, followed by a milk challenge to confirm diagnosis.
  - If diagnosis confirmed inform parents of the need to reintroduce dairy into the diet and when this is expected to happen/ what will be involved/support provided.
- International Code of Marketing - is this being adhered to by formula companies?

## 2. Initial Management

*How should initial presentation of suspected cows' milk allergy be best managed? What potential barriers could be encountered? How can these be overcome?*

- Best Managed
  - Health Visitors/Dietitians in GP Practice – playing a larger role in initial diagnosis.
  - Detailed family and feeding history – use of a validated tool to help with this, shared with all, including ED staff.
  - Regional pathway followed by all.
  - Same training for all HCP and consistent message delivered by all.
  - Explain to parents 1<sup>st</sup> prescription in a trial and emphasise the need for a milk challenge after 2-4 weeks.
  - Ensure patients see the right people at the right time – timely referral to dietetics if appropriate.
  
- Barriers Encountered
  - Parental expectations – of normal baby behaviour and of how long it will take to see an improvement in symptoms.
  - Step-up to AA too quickly.
  - Emotional effect of dietary restrictions on breastfeeding mothers.
  - Lack of GP time and knowledge on the topic.
  - GP “Fear of initiating” due to parental expectations.
  - “Bad Cop” Professionals – parents present at ED.
  - Inconsistent messages from different HCP.
  - Waiting times for Paeds/Dietitian referrals.
  
- How to Overcome
  - Parental Education – on normal newborn behaviour and common feeding challenges. On initiation of milk free diet, how long estimated to see improvements, emphasis on cows' milk being re-introduced as baby approaches first birthday.
  - Develop a timeline of AA Step-up, as 90% of babies should be able to be managed on EHF.
  - Health Visitors with Mental Health Training to help mothers struggling emotionally.
  - Simplified version of Pathway to make it more straightforward to follow and ensure consistent message from all HCP.
  - Transform care out of hospitals for suitable patients, dietitians in local settings/clinics.

### 3. Referral

*When should referral be made to other Healthcare Professionals? Which patients are appropriate to refer and when? What should ideally be carried out prior to referral and why?*

- Who should be referred?
  - Early intervention is important.
  - Suspected IgE mediated allergy, severe symptoms and faltering growth require urgent dietetic referral.
  - Capacity concerns with large numbers referred to Secondary Care.
  - When no “red flags” baby suitable to be managed under care of Health Visitor/Dietitian in Primary Care setting.
  - Who would be responsible for Triaging patients?
  
- What should ideally happen prior to referral?
  - Full history taken e.g. feeding, family, other symptoms.
  - Initial milk challenge to confirm diagnosis completed (unless severe symptoms)
  - Communication of all previous contact shared with Multidisciplinary Team.
  - Use of community resources to support breastfeeding mothers e.g. Breastfeeding support groups, peer support, Sure Start etc.

#### 4. **Review and Referral**

*How are patients with CMPA reviewed with a view to discontinuing their specialised formula? Where/how are reviews currently managed and is this the most appropriate setting? What issues may be encountered and how can they be overcome?*

- Where/ how reviews should be managed.
  - Important to discuss with parents from the outset the process and what to expect and when e.g. milk challenge, weaning, use of alternative milks e.g. coconut, oat etc. and milk ladder.
  - Informing parents from the start that formula is not a long term item and will be discontinued after baby reaches one year, if patient still allergic, counsel about the use of alternative milks e.g. oat, coconut.
  - Formula should be stopped by 12 months unless patient is under the care of Paediatricians.
  - Review quantity of formula prescribed after 6 months (and starting solid food).
  - Review of reflux symptoms and medications and also review of suitability to step down from Amino Acid formula.
  - 9 months – contact from Dietitian regarding initiation of the milk ladder.
  - Health Visitor to carry out 1 year review and identify any patients still on CMA formula – liaise with Dietitian/GP/Practice Based Pharmacist to review.
  
- What issues may be encountered how can they be overcome?
  - Parents may be resistant to make changes to infant formula, trial alternative milks etc. – Important to educate parents from the outset.
  - GP may be unsure who/how to step down use of CMA formula at 1 year – clear guidance on clinical system around review and stepdown. Alert on clinical system for patients who are over 12 months and still on CMA formula.
  - Patients over 12 months who have DNA at Paeds/Dietetics appointments but are still in receipt of CMA formula – what to do in this instance?

<b>Area: Education</b>	
<b>Action</b>	
1.	Update antenatal education for parents to include “normal” baby behaviour – expected feeding challenges, crying, wind, colic etc.
2.	Develop training materials for all healthcare professionals to ensure all are following the recommended guidance on which formulas to provide (e.g. initiation with EHF unless severe symptoms) and counselling patients on milk challenge after 2-4 weeks. E-learning may be an appropriate format for this.
3.	Produce an animation for parents about the milk challenge, which should be carried out after 2-4 weeks to confirm diagnosis of CMA for use on social media; hosting on <a href="http://niformulary.hscni.net/PatientZone/Nutrition/Pages/default.aspx">http://niformulary.hscni.net/PatientZone/Nutrition/Pages/default.aspx</a>

<b>Area: Pathway</b>	
<b>Action</b>	
1.	Paper on Nutrition Programme (Including Infant Milks) to be tabled at HSCB/PHA SMT –February 2020 for discussion and endorsement of proposed actions.
2.	Develop an updated regional pathway for Management of Suspected Cows’ Milk Allergy in Northern Ireland. This would be followed by all healthcare professionals in Northern Ireland, including emergency department staff. PHA to liaise initially with NI Paediatric Allergy Respiratory Group – next meeting 10 <sup>th</sup> February 2020
3.	Importance of sharing of full patient family and feeding history with all members of multidisciplinary team to be included in Guidance. This could be facilitated through triplicate forms in the Personal Child Health Record (PCHR)
4.	Continuity of contact with healthcare professionals in antenatal and post-natal period – helps to build a parent/professional relationship and provides continuity of care.

<b>Area: Use of Technology</b>	
<b>Action</b>	
1.	Develop review tools and adapt clinical systems to flag to GP surgeries when patients are over 12 months and should be reviewed/de-prescribed. GPiP, point of prescribing software etc.
2.	Promote resources for parents and carers e.g. explore use of animation etc. to aid review of patients at 12 months if still being prescribed CMA formula.
3.	Use of social media sharing videos, support links, info on milk challenge and re-introduction of cows' milk to parents.

<b>Area: Resources</b>	
<b>Action</b>	
1.	Ensure COMPASS reports are sent directly to Trust Leads for staff who are directly involved in management of CMA in each Trust.
2.	Email request to COMPASS review group to request addition of graph with number of babies aged 12 months + and aged 15 months + still being prescribed CMA formula to Trust COMPASS reports. <b>Completed</b>
3.	HSCB/PHA to Liaise with Mid Essex CCG to get an overview of their current CMA service. Completed Jan 2020

<b>Area: Communication</b>	
<b>Action</b>	
1.	Addition of workshop materials to Primary Care Intranet and email to all attendees of same. <b>Completed October 2019</b> <a href="http://primarycare.hscni.net/pharmacy-and-medicines-management/resources/nutritioninfant-nutrition/">http://primarycare.hscni.net/pharmacy-and-medicines-management/resources/nutritioninfant-nutrition/</a>
2.	Dissemination of this report to all attendees of the workshop. <b>Completed Feb 2020</b>
3.	Letter reminding of the importance of a consistent message to parents around trial of specialised formula for CMA to include milk challenge after 2-4 weeks to confirm diagnosis. To include: <ul style="list-style-type: none"> <li>• GPs</li> </ul>

	<ul style="list-style-type: none"><li>• Dietitians</li><li>• Health Visitors</li><li>• Emergency Department staff</li><li>• Out of Hours staff.</li></ul>
4.	<p>Update current HSCB Infant Feeding Guidelines <a href="http://niformulary.hscni.net/Formulary/Adult/PDF/PrimaryCare/Infant_Feeding_GuidelinesWeb.pdf">http://niformulary.hscni.net/Formulary/Adult/PDF/PrimaryCare/Infant_Feeding_GuidelinesWeb.pdf</a> to support agreed pathway (see point 1 in Pathway below.) This should include guidelines on suggested quantities for prescribing of CMA formula at initial trial, when diagnosis has been confirmed, after weaning has commenced 6-9 months and as weaning progresses 9-12 months. To be undertaken 20/21</p>