Lothian NHS Board

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Date 28/04/2025
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Our Ref 9930

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Dear

FREEDOM OF INFORMATION – COELIAC DISEASE

I write in response to your request for information in relation to coeliac disease.

Question:

- Under the Freedom of Information Act 2000, I would like to request the following information:
  - Any local guidelines or pathways used within your NHS health board to inform clinicians on coeliac disease diagnosis and follow-up care. We are interested in guidance for adults and children seen in any setting.
  - If your area does not have local guidance/pathways for coeliac disease, please specify which clinical guidelines (e.g. NICE, ESGPHAN, BSG) are recommended to clinicians.

Answer:

Information on pathways for adult and children is available on Refhelp (links below).

We also (children) have two formal guidelines specifically for screening in children / young people with T1DM and Down syndrome (these are locally agreed and the T1DM will differ from NHS England and actually from some other parts of Scotland – although shared with many areas).

These are both for Lothian use and are forward facing guidelines.

Adult and Paediatric pathways online.

Coeliac – RefHelp
https://apps.nhslothian.scot/refhelp/guidelines/paediatrics/paediatricgastrointestinal/coeliacpaediatric/

This information is exempt under Section 25 of the Freedom of Information (Scotland) Act 2002 - Information otherwise accessible

(1) Information which the applicant can reasonably obtain other than by requesting it under section 1(1) is exempt information.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: https://org.nhslothian.scot/FOI/Pages/default.aspx

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive
Enc.

Coeliac Disease screening in children and young people with Down Syndrome

Title: A Screening strategy for Coeliac Disease in Children and young people with Down Syndrome			
Date effective from:	08/05/2024	**Review date:**	08/05/2027
Approved by:	Medical Guidelines Committee		
Approval Date:	08/05/2024		
Author/s:	Consultant Gastroenterologist NHS Lothian, RHCYP ST8 in Paediatrics, Community Paediatrics, NHS Lothian, RHCYP Clinical Director, Community Paediatrics NHS Lothian, RHCYP Service Development Lead, Community Paediatrics Lothian, SJH		
Executive Lead:	Associated Medical Director		
Target Audience:	All secondary health care professionals dealing with children and YP under 18 with Down Syndrome		
Supersedes:			
Keywords (min. 5):	Down Syndrome; coeliac disease; screening; serology (TTG); HLA typing		

Coeliac Disease screening in children and young people with Down Syndrome

Version Control

Date	Author	Version/Page	Reason for change

Coeliac Disease screening in children and young people with Down Syndrome

NHS Lothian

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1.0 Purpose

This guidance is intended for clinicians and health care professionals in Lothian who are involved with the care of children and young people (YP) with Down Syndrome (DS) and to inform discussion regarding the need for screening for Coeliac disease (CD) which is recognised as an 'at-risk' condition by specialist organisations and to offer options for how and when to offer testing/ screening for the condition after counselling of a family. It also advises what options there are for testing and what opportunities there are for timing of testing.

2.0 Scope

This guidance is intended for children and young people with DS under age 18 in NHS Lothian

3.0 Definitions

Down Syndrome (DS) – all Individuals with Trisomy 21

Coeliac disease (CD) – an autoimmune enteropathy in a genetically susceptible individual, dependent on gluten (wheat, barley, rye) and which reverses on a Gluten Free Diet (GFD)

DQ typing – HLA testing via Blood Transfusion Service (BTS) Tissue typing laboratory

Screening – a process of actively checking for a condition in a group of patients seen as at increased risk

4.0 Roles and responsibilities

Clinicians dealing with patients with DS, primarily the community paediatrics team, should be aware of the association and discuss the condition with families and to inform them of risk and potential for development of CD as part of the management of children and young people with DS in the context of other healthcare issues (eg thyroid screening). All should be prepared for a discussion about CD, when appropriate and to seek further advice as required from the coeliac service and to utilise opportunities to discuss screening for the condition at appointments as part of a healthcare assessment and clinical reviews.

5.0 Main content and evidence base

Why should we screen for Coeliac Disease in Down syndrome and when?

We know that in the general population, the prevalence of coeliac disease is estimated to be 1:100 in the UK if we were to screen the population, but this is not currently advised. ESPGHAN recommendations 2012 and 2020 detail at-risk patients[1,2] . However, BSPGHAN[3] (British Society of

Paediatric Gastroenterology, Hepatology and Nutrition) and NICE[4,5] recommend there should be a low threshold for investigating children with associated ('at-risk') conditions, as it is recognised that many cases remain undiagnosed.

Associated conditions include (estimated lifetime prevalence):

- Type I diabetes (≥ 8%)
- Selective IgA deficiency (1.7%–7.7%)
- **Down Syndrome (5%–12%)[5-7]**
- Williams Syndrome (8.2%)
- Turner Syndrome (4.1%–8.1%)
- Autoimmune thyroiditis (~15%)
- Autoimmune liver disease
- Unexplained raised transaminases without known liver disease
- Intussusception
- Dermatitis herpetiformis
- Relatives of coeliac patient: – First-degree relative (~10%) – HLA-matched sibling (~30%–40%) – Monozygotic twin (~70%)

Current Guidance and BSPGHAN Flowchart – see Appendix 1 and 2

Information from BSPGHAN 2013[3]

The BSPGHAN coeliac disease working group modified the then ESPGHAN 2012 guidance with advice in asymptomatic children with an associated condition to consider HLA typing as well as standard serology. If an individual is HLA DQ2/DQ8 positive: continue surveillance (optimum frequency for repeat blood testing unclear, but every 3 years is reasonable if asymptomatic) and perform endoscopy if symptomatic. If HLA DQ2/DQ8 negative: development of CD highly unlikely. Discontinue regular antibody screening but clinical review if suggestive symptoms develop.

Information from NICE NG 20 AND QS 134 [4,5]

NICE guidance has no clear messaging on DQ testing as they did not consider the current guidance from ESPGHAN or BSPGHAN at the time. For DS, NICE states in NG 20 (2015) to 'consider' serological testing[4]. This is a less strong recommendation. They then published a Quality Standard QS 134 in 2016 that stated : 1: serological testing in coeliac disease suggests, healthcare professionals offer a serological test for coeliac disease to people at 'increased risk' or with symptoms of coeliac disease and ensure that people have been following a gluten-containing diet for at least 6 weeks before the test[5].

NICE NG20 - People deemed at increased risk or with symptoms of coeliac disease:

- persistent unexplained abdominal or gastrointestinal symptoms
- faltering growth
- prolonged fatigue
- unexpected weight loss
- severe or persistent mouth ulcers
- unexplained iron, vitamin B12 or folate deficiency
- type 1 diabetes, at diagnosis
- autoimmune thyroid disease, at diagnosis
- adults who meet the irritable bowel syndrome diagnostic criteria
- first-degree relatives of people newly diagnosed with coeliac disease

1.1 Recognition of coeliac disease

Offer serological testing for coeliac disease to:

• people with any of the following: — persistent unexplained abdominal or gastrointestinal symptoms
— faltering growth
— prolonged fatigue
— unexpected weight loss
— severe or persistent mouth ulcers
— unexplained iron, vitamin B12 or folate deficiency
— type 1 diabetes, at diagnosis
— autoimmune thyroid disease, at diagnosis
— irritable bowel syndrome (in adults)
• first-degree relatives of people with coeliac disease.

1.1.2 Consider serological testing for coeliac disease in people with any of the following:

• metabolic bone disorder (reduced bone mineral density or osteomalacia)
• unexplained neurological symptoms (particularly peripheral neuropathy or ataxia)
• unexplained subfertility or recurrent miscarriage
• persistently raised liver enzymes with unknown cause
• dental enamel defects
• Down syndrome
• Turner syndrome

HLA typing for coeliac disease in Down Syndrome and its utility

The suggested management approach from BSPGHAN (Appendix 2) for asymptomatic cases in 'at-risk' individuals has been modified and applied specifically to individuals with DS and is on page 8. Human Leukocyte Antigen (HLA) genes are often associated with certain conditions. They are also known as disease association antigens (or more accurately, permissibility antigens). People with coeliac disease are known to have one or more of HLA DQ 2.5 (commonest), HLA DQ8 (less

common) or HLA DQ2.2 (least common) and are often found in combination in 99.6% of known CD patients[6]. Having that 'genetic factor' might mean that you may develop coeliac disease in your lifetime, but it does not mean that you will definitely develop it. The risk of developing coeliac disease without one of these HLA types is very rare and less than 1%. A negative test is therefore very helpful. A positive result can allow some degree of risk stratification. We are not the first group to propose DQ typing, it has been detailed by teams from the Netherlands in 2000 and in 2009[7]. This presents an opportunity for coeliac screening in Children with DS as they are a little more likely to carry the DQ type (around 60%) than the general population which is up to 40% of the population. This means that those 'at risk' and who carry a permissibility antigen may have a risk of approximately 10% of developing the condition but means that the vast majority who carry the ability will not develop CD. Data from NHS Lothian and Fife, suggests up to 40% of children and young people with DS could be eliminated from long-term coeliac serology screening[8,9].

DQ typing does not require exposure to a gluten containing diet and therefore testing could be performed in early life prior to serology and can be performed as an isolated test, or in combination with serology in a gluten exposed individual. This testing should be discussed with families and testing offered as part of an 'opt-in' plan, given that this testing and its implications needs to be understood by the families and the option not to be tested at all is entirely valid.

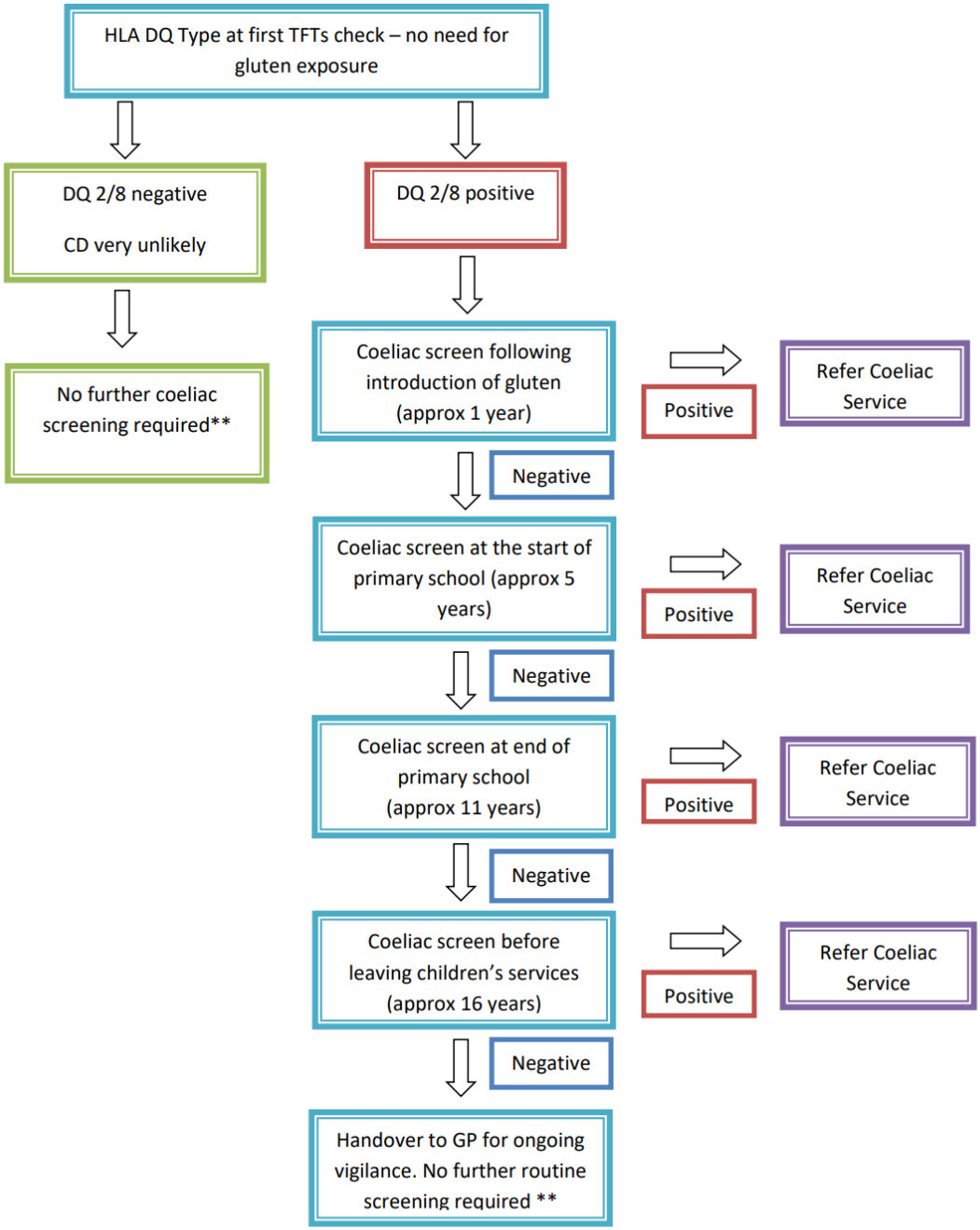
The DQ test is sent to the Blood Transfusion Service (BTS) HIE laboratory RIE, 2mls minimum EDTA. It is a paper request and form in Lothian and is attached to this document as an Appendix 3. This is available from the phlebotomy rooms at RHCYP. Results are now uploaded to SCI store by the lab but will not appear on your results workbench.

Standard serology testing for coeliac disease

Coeliac serology testing (a coeliac screen) is standard practice in symptomatic patients suspected to have the condition in gluten exposed individuals. Clearly if a patient is symptomatic, testing at any age over 6 months may be helpful but if asymptomatic the earliest we would screen would be in the 2nd year of life, for example at over 12 months of age. This is a venous blood test which is sent in NHS Lothian to Biochemistry labs at WGH (serum, gel tube 1ml minimum). This can be done along with other relevant bloods eg TFTs and other bloodwork. In Lothian a Total IgA level is not required (unless there is a specific reason) due to an automatic system where Total IgA is performed of the TTG IgA is below 0.6 g/L and a TTG IgG will automatically be performed if the Total IgA level is below 0.2 g/L.

HOW TO DO IT - Options for testing (see Flowchart and also as Appendix 1)

1. **HLA test before gluten exposure (can be done on first venous sampling)**
2. **HLA test and coeliac serology when gluten exposed**
3. **Coeliac serology test only when gluten exposed**
4. **Please note, these time points are suggestions and not mandatory, nor is testing, and must be done after parental counselling**



Nb. Parental consent must be sought along with explanation of the process prior to commencing screening

**Offer a coeliac serology screen at any point if symptomatic regardless of DQ status

6.0 Associated materials

Appendix 1 – Flow chart for investigation

Appendix 2- BSPGHAN Flowchart from 2013

Appendix 3 – BTS Tissue typing form

7.0 Stakeholder consultation

NHS Lothian Paediatric Coeliac service (Dr Peter Gillett, Consultant Gastroenterologist RHCYP)

Community Child Health team

Dr Leanne Brennan, ST8, Community Child Health NHS Lothian, RHCYP

Dr Anna Chillingworth, Medical Director, Community Child Health NHS Lothian, RHCYP

Dr Jennifer Mackenzie, Service Development Lead, Community Child Health NHS Lothian, SJH

Dr Anna Dall, Consultant Paediatrician, NHS Borders

8.0 Monitoring and review

Next review January 2027

References

1.Husby S, Koletzko S, Korponay-Szabo IR*, et al.* European Society for Pediatric Gastroenterology, Hepatology, and Nutrition guidelines for the diagnosis of coeliac disease. *Journal of Pediatric Gastroenterology and Nutrition*. 2012;54:136-60.

2.Husby S, Koletzko S, Korponay-Szabó I, et al. European society paediatric gastroenterology, hepatology and nutrition guidelines for diagnosing coeliac disease 2020. J Pediatr Gastroenterol Nutr 2020;70:141–56.

3. Murch S, Jenkins H, Auth M*, et al.* Joint BSPGHAN and Coeliac UK guidelines for the diagnosis and management of coeliac disease in children. *Archives of Disease in Childhood*. 2013;98:806-11.

4. NICE Coeliac disease: recognition, assessment and management (NG 20, 2015) https://www.nice.org.uk/guidance/ng20 Accessed 14.1.24

5. NICE Coeliac disease: Quality Standard (QS 134, 2016) https://www.nice.org.uk/guidance/qs134 Accessed 14.1.24

6. Tye-Din JA, Cameron DJ, Daveson AJ, et al. Appropriate clinical use of human leukocyte antigen typing for coeliac disease: an Australasian perspective. *Intern Med J* 2015;45:441-50

7. Wouters J, Weijerman ME, van Furth AM, et al. Prospective human leukocyte antigen, endomysium immunoglobulin A antibodies, and transglutaminase antibodies testing for celiac disease in children with Down syndrome. J Pediatr. 2009. 154(2):239-42

8. Sumner C, et al. G368 DQ typing is effective in coeliac disease screening in children and young people with down syndrome in South East Scotland. Archives of Disease in Childhood 101 (Suppl 1): A215.2-A216. Oral presentation at RCPCH Liverpool April 2016.

9. Lewis T, et al. HLA-typing as cost effective screening test for coeliac disease in children with Down Syndrome. Frontline Gastroenterology. 13 (Suppl 1): A3-A4. Oral presentation at BSPGHAN Birmingham April 2022.

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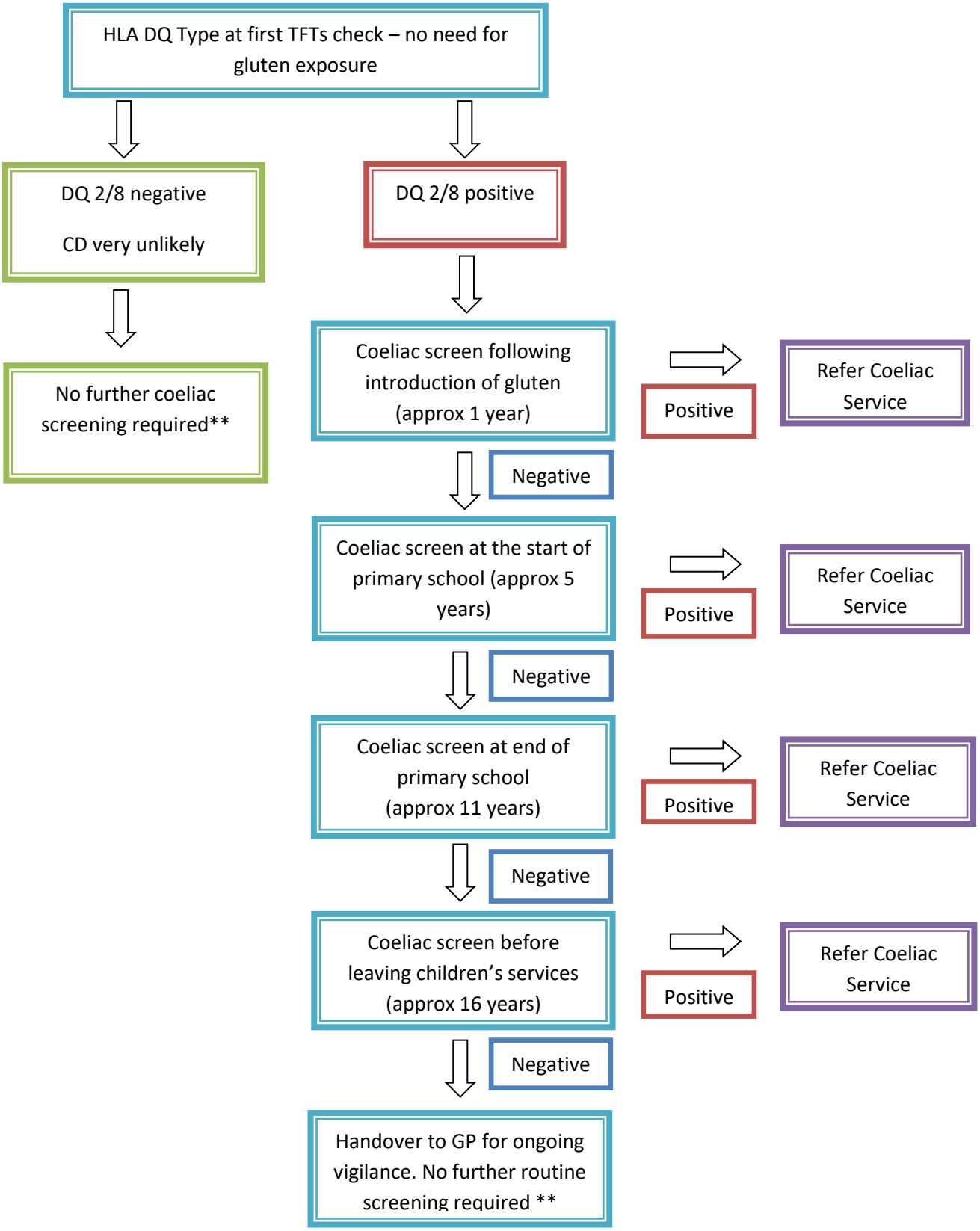
Appendix 1: Proposed HLA typing and coeliac screening schedule in children with Down Syndrome



Nb. Parental consent must be sought along with explanation of the process prior to commencing screening

**Offer a coeliac serology screen at any point if symptomatic regardless of DQ status

Appendix 2- from CUK/ BSPGHAN Guidance 2013

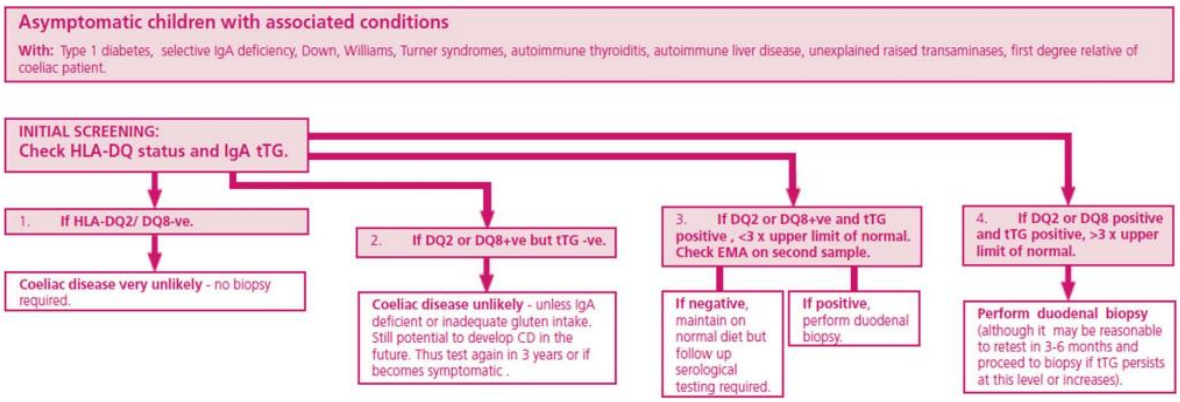
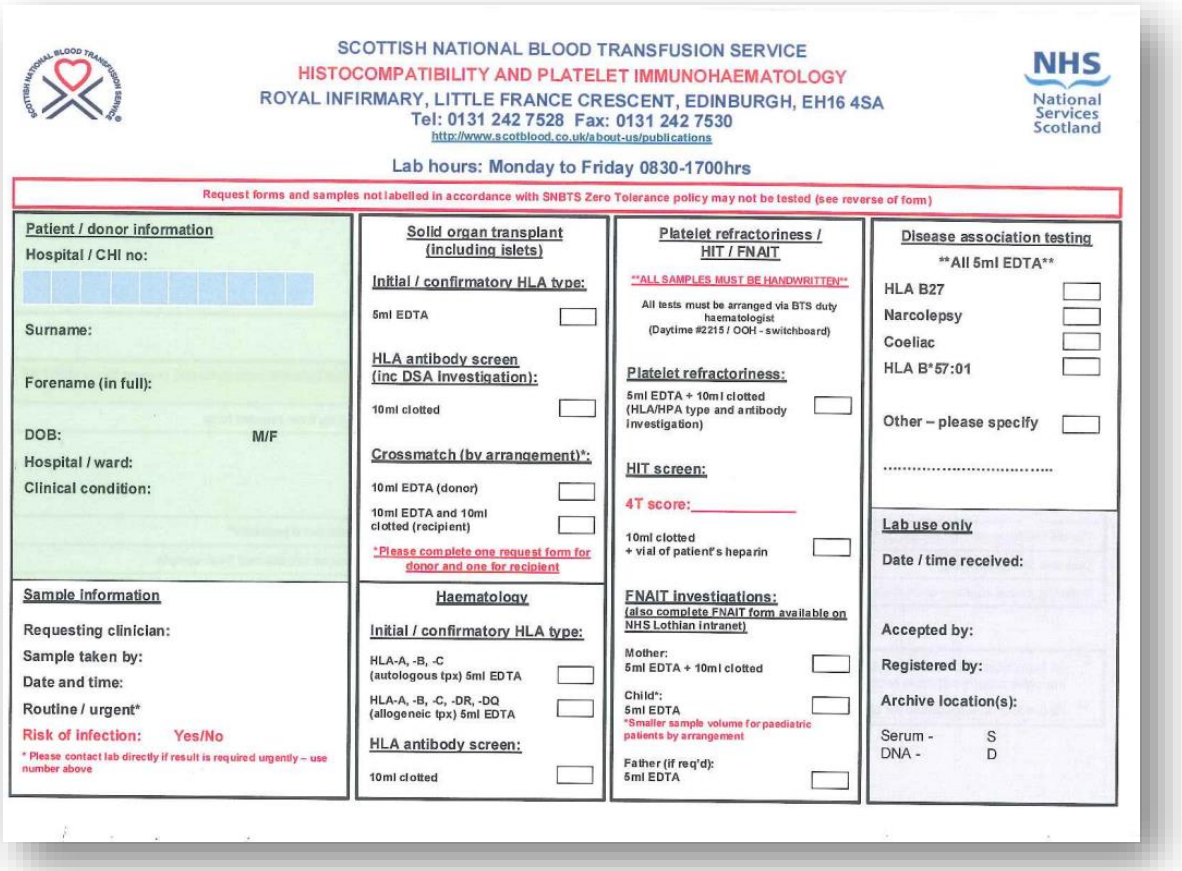


Figure 2 Outline stratagem for asymptomatic children with associated conditions.

Appendix 3- HLA typing form



SCOTTISH NATIONAL BLOOD TRANSFUSION SERVICE
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NHS National Services Scotland

Lab hours: Monday to Friday 0830-1700hrs

Request forms and samples not labelled in accordance with SNBTS Zero Tolerance policy may not be tested (see reverse of form)

Patient / donor information
Hospital / CHI no:
Surname:
Forename (in full):
DOB: M/F
Hospital / ward:
Clinical condition:

Sample information
Requesting clinician:
Sample taken by:
Date and time:
Routine / urgent*
Risk of infection: Yes/No
* Please contact lab directly if result is required urgently – use number above

Solid organ transplant (including islets)
Initial / confirmatory HLA type:
5ml EDTA
HLA antibody screen (inc DSA investigation):
10ml clotted
Crossmatch (by arrangement)*:
10ml EDTA (donor)
10ml EDTA and 10ml clotted (recipient)
*Please complete one request form for donor and one for recipient

Haematology
Initial / confirmatory HLA type:
HLA-A, -B, -C (autologous tpx) 5ml EDTA
HLA-A, -B, -C, -DR, -DQ (allogeneic tpx) 5ml EDTA
HLA antibody screen:
10ml clotted

Platelet refractoriness / HIT / FNAIT
ALL SAMPLES MUST BE HANDWRITTEN
All tests must be arranged via BTS duty haematologist (Daytime #2215 / OOH - switchboard)
Platelet refractoriness:
5ml EDTA + 10ml clotted (HLA/HPA type and antibody investigation)
HIT screen:
4T score:
10ml clotted + vial of patient's heparin
FNAIT investigations: (also complete FNAIT form available on NHS Lothian intranet)
Mother: 5ml EDTA + 10ml clotted
Child*: 5ml EDTA
*Smaller sample volume for paediatric patients by arrangement
Father (if req'd): 5ml EDTA

Disease association testing
All 5ml EDTA
HLA B27
Narcolepsy
Coeliac
HLA B*57:01
Other – please specify
.....

Lab use only
Date / time received:
Accepted by:
Registered by:
Archive location(s):
Serum - S
DNA - D

Coeliac Disease screening in Children and Young People with Type 1 diabetes

Title: Coeliac Disease screening in Children and Young People with Type 1 diabetes			
Date effective from:	23/01/2025	**Review date:**	22/01/2028
Approved by:			
Approval Date:	Click here to enter a date.		
Author/s:	Consultant Gastroenterologist NHS Lothian, RHCYP Consultant in Paediatric Diabetes and Endocrinology NHS Lothian, RHCYP		
Executive Lead:	XXXXXXXXXXXXXX		
Target Audience:	All health care professionals dealing with Children and Young People under 18 with Type 1 diabetes		
Supersedes:			
Keywords (min. 5):	Type 1 diabetes; coeliac disease; screening; serology; tissue transglutaminase; HLA DQ typing		

Coeliac Disease screening in Children and Young People with Type 1 diabetes

Version Control

Date	Author	Version/Page	Reason for change

Coeliac Disease screening in Children and Young People with Type 1 diabetes

NHS Lothian

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1.0 Purpose

This guidance is intended for all clinicians in NHS Lothian who are involved with the care of children and young people (CYP) 18 years and under with Type 1 diabetes (T1DM) and to inform discussion regarding the need for screening / testing for Coeliac disease (CD) which is recognised as an 'at-risk' condition in T1DM and for pragmatic options for how and when to offer testing / screening for the condition after counselling of a patient and their family.

2.0 Scope

This guidance is intended for children and young people with T1DM under age 18 in NHS Lothian.

3.0 Definitions

Type 1 diabetes (T1DM) – all individuals with T1DM.

Coeliac disease (CD) – an autoimmune enteropathy in a genetically susceptible individual, dependent on gluten (wheat, barley, rye) and which reverses on a Gluten Free Diet (GFD).

DQ typing – HLA testing via Blood Transfusion Service (BTS) tissue typing laboratory.

Screening – a process of actively checking for a condition in a group of patients seen as at increased of developing that condition.

4.0 Roles and responsibilities

All healthcare professionals dealing with patients with T1DM, primarily the paediatric diabetes team, should be aware of the association and discuss the condition with families to inform them of risk and potential for development of CD. All should be prepared for a discussion about CD, when appropriate and to seek further advice as required from the coeliac service. Opportunities to discuss screening for the condition should be taken at appointments as part of a healthcare assessment and clinical reviews.

5.0 Main content and evidence base

Background

Patients with T1DM are seen as an at-risk group for coeliac disease. Various and multiple reports suggest that at least 5% (1 in 20) patients with T1DM also develop coeliac disease (CD) in their lifetime. Several guidelines have been published for CD screening and strategies to take over the last few years. [1-3] Historically, NICE NG20 advised testing for CD at T1DM diagnosis using serology as a screen (NICE NG20) and the subsequent Quality Standard (QS 134) and many parts of the UK do this as routine, perhaps unaware now of the increasing literature around 'coeliac autoimmunity'.[4,5] In Southeast Scotland, we have screened patients with T1DM since 1995. We have in the last 10+ years deferred serology testing until approximately 4 months after T1DM diagnosis unless testing at diagnosis of T1DM is indicated (due to GI or other symptoms suggestive of CD). Unlike other at-risk conditions, the utility of DQ testing to identify those not at risk is less helpful in T1DM, as only 6% of a cohort within Lothian and Grampian were negative when tested [6,7].

There is evidence of CD 'autoimmunity' in T1DM, and many symptomatic patients may benefit from a watch and wait approach (i.e. defer endoscopy in favour of repeat serology testing and monitoring for symptoms). A significant number of patients who have antibody positivity will not be clinically affected by adopting this approach and it allows families time to understand that development of CD may occur. During this time there is ongoing monitoring of HbA1C, growth and symptoms. Ultimately an upper endoscopy (UGIE) may be required to fully clarify [8-11]. Families are actively involved in the decision making about proceeding to further testing or GFD.

Standard serology testing for coeliac disease in NHS Lothian

Coeliac serology testing (a coeliac screen, TTG IgA) is standard practice in symptomatic patients suspected to have the condition in gluten exposed individuals. If a patient is symptomatic, testing at any age over 6 months may be helpful. If asymptomatic, screening should not be carried out before the age of 12 months of age. Coeliac serology is a venous blood test (serum, gel tube 1mL minimum) processed at the WGH Biochemistry labs. In Lothian a total IgA measurement does not need to be requested routinely in addition as total IgA is automatically performed if the TTG IgA is below 0.6 U/mL. A TTG IgG will then be measured if the total IgA level is below 0.2 g/L. In Lothian, the normal range for coeliac serology (Lothian assay is Orgentec ®, Mainz, Germany) is 0.1 to 5.0 U/mL.

Notification of positive coeliac serology in NHS Lothian

The laboratory at WGH routinely notifies the requestor of the positive serology test (Endocrinology consultant, nurse specialist or less commonly the GP) in the usual manner via TRAK results workbench. The CYP coeliac service are also notified directly by the laboratory of all new positive results. The coeliac service dietitians via the CYP coeliac dietetic service email, loth.cypcoeliac@nhs.scot, will contact the requestor about the positive result, requesting further details and to discuss a plan of action. For patients within the diabetes service, the coeliac service will contact the diabetes team member / responsible consultant about the test and discuss the results and make a shared plan, using the strategies outlined below (and in flowchart Figure 1, page 9).

The diabetes team will inform the family about the results and take the plan forward, with ongoing advice from the Coeliac Service as required. Advise all patients to remain on a gluten containing diet until investigations have been concluded.

Please note, NHS Borders and NHS Fife use different assays. We are not automatically notified by their laboratories, but by the local teams referring / discussing with us. Any positive results should be discussed with the NHS Lothian Coeliac Service by the local team.

Standard operating procedure for initial management of serology positive patients with T1DM

Symptomatic Patients (this may depend on symptoms, ie typical or atypical)

- Anti TTG IgA > 50, repeat serology at next opportunity.
    - If repeat result > 50, refer to diabetes dietitians for GFD – and discussion with family re a 'no-biopsy' diagnosis or endoscopy if they wish
    - If repeat result 5 - 50, diabetes team to discuss with family recommendation for referral for endoscopy.
- Anti TTG IgA 10-50, repeat serology in 3 to 4 months.
    - If repeat result 10-50, diabetes team to discuss with family recommendation for refer for upper endoscopy.
    - If repeat result > 50, refer to diabetes dietitians for GFD.
- Anti TTG IgA 5-10 (low positive), discuss amount of gluten exposure, and advise to maximise if required, and repeat after 3 to 4 months.
    - If repeat result 5 - 50, refer for upper endoscopy.
    - If repeat > 50, refer to diabetes dietitians for GFD.
- Selective IgA deficiency (SIgAD) with anti TTG IgG raised at any level (normal is under 10 U/mL), repeat serology.
    If repeat result raised, refer for endoscopy. Note: 1. patients with SIgAD cannot be diagnosed using the no-biopsy strategy irrespective of titre value. 2. If symptomatic and repeat is normal, discuss merits of endoscopy anyway.

Asymptomatic Patients, ANY anti TTG IgA titre level

- Repeat the test at 6 monthly intervals. Watch for symptom development and monitor glucose control, growth, and antibody titre (i.e. upward trend).

- Repeat earlier if symptoms develop, and / or consider earlier listing for endoscopy.
- If serology remains positive at 18 months of follow up, despite being asymptomatic, discussion with family and refer for discussion with coeliac team and likely upper endoscopy.

Outcomes to be discussed by clinician with young person and family following upper endoscopy and biopsy

- Definite evidence of coeliac disease – refer to diabetes dietitians for gluten-free diet (GFD)
- No evidence of coeliac disease (for example, serology test normalised on day of scope or is 'potential coeliac disease' with positive serology and normal biopsies).
    - If symptomatic, discussion regarding a trial of GFD.
    - If asymptomatic, repeat serology annually. Watch for symptom development and monitor glucose control, growth, and antibody titre (i.e. upward trend). Repeat earlier if symptoms develop, and/or consider earlier listing for endoscopy.

Actions if previously elevated anti-TTG has normalised.

- In symptomatic patients, consider referral for endoscopy, although likely not coeliac disease
- In asymptomatic patients, repeat serology after 6 months.
    - If repeat test normal, return to routine monitoring as per diabetes pathway.
    - If repeat test raised, continue to monitor 6-monthly, as per pathway for asymptomatic patients with raised serology.

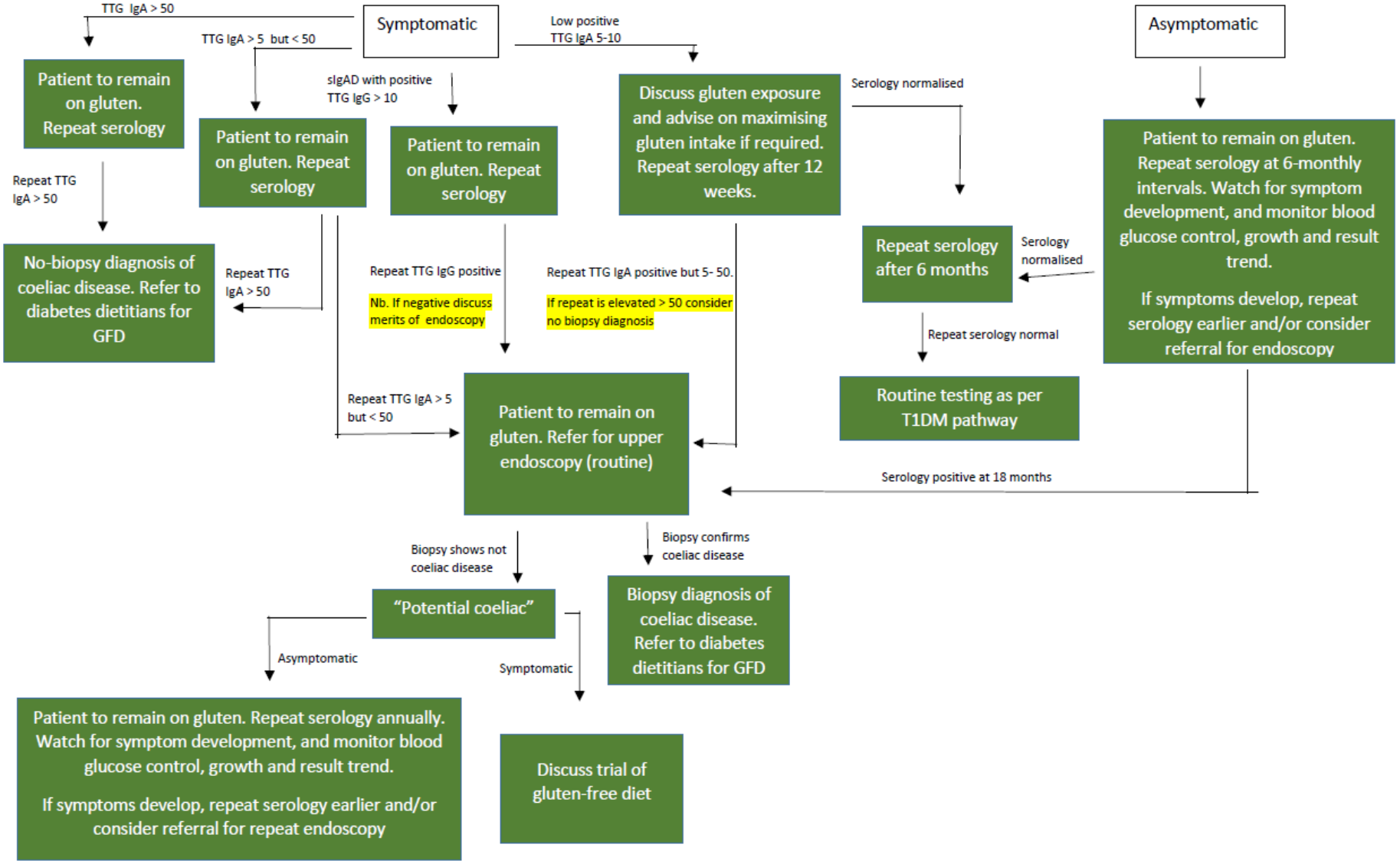
Contact Points:

RHCYP Coeliac team: loth.cypcoeliac@nhs.scot

RHCYP Diabetes team: loth.rhcypdiabetes@nhs.scot

NHS Lothian Paediatric Coeliac Service

Standard Operating Procedure for the initial management of raised coeliac screen results in patients with T1DM



6.0 References

1.Husby S, Koletzko S, Korponay-Szabo IR*, et al.* European Society for Pediatric Gastroenterology, Hepatology, and Nutrition guidelines for the diagnosis of coeliac disease. *Journal of Pediatric Gastroenterology and Nutrition*. 2012;54:136-60.

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7.0 Stakeholder consultation

NHS Lothian Paediatric Coeliac service

Consultant Gastroenterologist NHS Lothian RHCYP

CD service NHS Lothian RHCYP

Diabetes Service NHS Lothian RHCYP

Consultant in Paediatric Diabetes and Endocrinology NHS Lothian RHCYP

RHCYP Diabetes team

8.0 Monitoring and review

Next review January 2028