PMCHS — Programmed Mast Cell Hyperreactivity Syndrome

Letter for the physician — Child

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Objective: to open a constructive discussion on the mast cell hypothesis, without confrontation.

Subject: Clinical observations regarding [Child's name] — suspected mast cell hyperreactivity (MCAS)

Doctor,

I am writing to share with you some elements regarding the health of [Child's name], who has been presenting for several months with recurrent multi-system reactions suggesting a mast cell activation background. I would like to present the clinical elements, the diagnostic limitations recognised in the specialist literature, and the approach we are considering.

1. Observed Symptoms

For several months, [Name] has been presenting recurrent, multi-system episodes correlated with certain identified triggers (foods, stress, heat, exertion…). They include:

- Immediate cutaneous manifestations after certain foods (redness, patches, pruritus, dermographism).
- Fluctuating digestive symptoms (abdominal pain, alternating severe diarrhoea/constipation, nausea). (Gastrointestinal symptoms are very common in mast cell disorders — tacanow.org)
- Acute neuro-behavioural reactions (sudden irritability, hypo-reactivity, agitation, "light-headedness" after certain foods, abrupt change in state). (Mast cells influence the nervous system via neuroactive mediators — jacionline.org, clevelandclinic.org)
- Neurovegetative signs (pallor, sweating, sudden irritability).

We have been documenting these episodes using detailed observation forms in order to identify reproducible patterns. These observations are attached to this document.

2. Regarding MCAS Diagnostic Criteria (JACI 2024)

I understand that the official diagnosis of MCAS rests on three criteria:

- Recurrent acute polysystem involvement
- Transient elevation of a mast cell mediator (tryptase, PGD2, LTE4, urinary N-methylhistamine) measured during the episode
- Response to targeted treatment (antihistamines, sodium cromoglycate, anti-leukotrienes…)

However, the authors themselves acknowledge several important limitations in applying these criteria, particularly in paediatrics:

- Mast cell mediators are highly volatile and difficult to capture at the right moment — their measurement requires sampling within a very short window after episode onset. (mastcellaction.org — updated diagnostic criteria 2025)
- In paediatrics, symptoms are often non-verbalised, subtle, or primarily behavioural — making them difficult to formally recognise and document. (jacionline.org — JACI 2024)
- The logistics of sampling during an acute episode are often impractical in young children: unpredictable episodes, short time windows, impossibility of reaching an appropriate facility immediately.
- Urinary N-methylhistamine is not a universally accepted marker in all protocols, and its absence does not allow the diagnosis to be excluded.

- Many clinicians are not yet familiar with MCAS criteria or do not apply them — a fact explicitly acknowledged in specialist publications. (JACI: In Practice 2026, healthline.com)

Thus, strict biological confirmation is often impractical in young children, and its absence is not sufficient to exclude the diagnosis or justify the absence of management.

3. What We Are Asking

We are not seeking to "put a label" on our child, but rather to:

- Understand [Name]'s recurrent reactions and their probable mechanism.
- Identify and avoid triggers.
- Adapt diet and environment to reduce the frequency and intensity of episodes.
- Assess the relevance of a trial treatment (H1/H2 antihistamines, sodium cromoglycate, anti-leukotrienes…), according to your clinical judgement.
- Rule out other relevant differential diagnoses.

We would be grateful if you would agree to:

- Read the attached clinical observations and discuss them with us.
- Help us determine safe strategies to improve [Name]'s comfort.
- Discuss a pragmatic management trial, according to your judgement.
- Prescribe serum tryptase and urinary N-methylhistamine testing. We are aware these tests may not confirm anything, but they could help guide next steps.

4. Our Objective

Our approach is guided solely by the desire to improve our child's comfort and safety, to prevent potentially severe reactions, and to work with you in a spirit of trust — taking into account the limitations of current criteria and the reality of their application in paediatrics.

We sincerely thank you for your attention and your support.

[First name Last name — Parent / Legal guardian]

[Date]