PMCHS — Programmed Mast Cell Hyperreactivity Syndrome

Letter for the physician — Adult

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

Subject: Clinical observations — suspected mast cell hyperreactivity (MCAS)

Doctor,

I am writing to share with you some elements regarding my health, with the aim of discussing them in a structured and constructive manner.

For several months, I have been experiencing recurrent multi-system episodes that are consistent, according to the specialist literature, with a mast cell hyperreactivity background (Mast Cell Activation Syndrome, MCAS). I would like to present the clinical elements, the recognised diagnostic limitations, and the approach I am considering.

1. Observed Symptoms

These episodes are recurrent, multi-system, and correlated with certain identified triggers (foods, stress, heat, physical exertion, hormones…). They include:

- Immediate cutaneous manifestations (redness, urticaria, dermographism, diffuse pruritus).
- Fluctuating digestive symptoms (abdominal pain, nausea, diarrhoea, constipation, reflux).
- Neurovegetative reactions (tachycardia, hot flushes, feeling of malaise, brain fog).
- Neurological symptoms (headaches, post-reactive fatigue, sudden irritability, sensory hypersensitivity).
- Partial response to H1 antihistamines, which in itself constitutes a diagnostic argument according to MCAS criteria (JACI 2024).

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

2. Regarding 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 (serum tryptase, PGD2, LTE4, urinary N-methylhistamine) measured during the episode
- Response to targeted anti-mediator treatment (antihistamines)

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

- Mediators are highly volatile — their measurement requires sampling within a very short window after episode onset, which is often impractical in routine care.
- 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).
- A pragmatic clinical diagnosis — based on polysymptomatology, identified triggers, and treatment response — is recognised as valid in cases where biological confirmation is difficult to obtain.

Thus, the absence of a formal biological marker is not sufficient to exclude MCAS, and does not justify the absence of management.

3. My Request

I am not seeking a labelled diagnosis, but rather to:

- Better understand my reactive background.
- Identify and avoid triggers.
- Reduce the impact of reactions on my quality of life and functional capacity.
- Assess the relevance of a trial treatment (H1/H2 antihistamines, sodium cromoglycate, anti-leukotrienes…).

I would be grateful if you would agree to:

- Review my clinical observations and the attached forms.
- Help me rule out other relevant differential diagnoses.
- Discuss a pragmatic management trial, according to your clinical judgement.
- Prescribe serum tryptase and urinary N-methylhistamine testing.

4. My Objective

My intention is simply to improve my quality of life, to prevent potentially severe reactions, and to work with you with respect for your expertise and current technical limitations.

I remain available for any further exchange, and sincerely thank you for your attention.

[First name Last name]

[Date]