

ConnectED Health Position Statement: Clinical Advisory on Unverified Protocols in Complex Chronic Illness

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Subject: Clinical Risks of Endorsing Non-Evidence-Based Protocols in hEDS, POTS, MCAS,

and Related Conditions

Purpose of this Advisory

As a leading research and patient-advocacy initiative committed to evidence-based care in connective tissue disorders, ConnectED Health expresses concern over the growing trend of healthcare professionals promoting unverified "wellness protocols" that lack peer-reviewed evidence and clinical oversight. One such example is the recently circulated "Born Free Protocol," which is being recommended by clinicians in Australia and abroad without adequate scientific validation.

Background

Patients with hEDS, POTS, MCAS, and related neuroimmune disorders often seek answers outside the conventional system due to widespread misdiagnosis and neglect. This systemic failure has created fertile ground for pseudoscientific interventions to take root. However, even in cases of diagnostic neglect, clinicians bear an ethical obligation to avoid endorsing protocols that:

- Lack peer-reviewed validation
- Have not undergone pharmacovigilance or safety trials
- Do not provide transparent methodology or ingredient rationale
- Risk destabilising already compromised autonomic, metabolic, or immune systems

Risks Identified in the "Born Free Protocol"

- Polypharmacy Without Personalisation: Combines adaptogens, high-dose iodine, methyl donors, detox agents, and herbal preparations without SNP testing (e.g., MTHFR, COMT, CBS) or gut profiling.
- No Titration Guidance: Protocol offers no indication of staged introduction, risk thresholds, or biochemical monitoring.
- **Ignores Known Pathophysiology**: hEDS patients often have impaired methylation, sulfation, autonomic instability, and mast cell hypersensitivity. Many of the ingredients in the protocol are contraindicated in these settings.
- Absence of Clear Scientific Basis: The references provided do not meet the standard of peer-reviewed or clinically validated literature.







Professional Responsibility and Legal Risk

Clinicians endorsing such protocols may inadvertently:

- Breach AHPRA codes of conduct regarding evidence-based practice
- Create harm through destabilising metabolic or autonomic systems
- Be held liable for adverse events resulting from non-validated interventions

ConnectED Recommendations

- 1. **Do Not Endorse Unverified Protocols**: Until full peer-reviewed evaluation, protocols like Born Free should not be used in clinical contexts.
- 2. **Advocate for Individualised Care**: All interventions must consider the patient's genetic, biochemical, and microbial context.
- 3. **Refer to Systems-Based Rescue Guides**: Use established resources such as the ConnectED Rescue Protocols, which are physiologically grounded, transparently cited, and designed to work with patient-specific data.
- 4. **Report Concerns**: If a clinician becomes aware of harm resulting from these protocols, we recommend documentation and, where necessary, reporting to relevant bodies.

ConnectED Health will continue to produce and share peer-reviewed, systems-based models of care designed to support the unique physiology of this cohort. We encourage all clinicians to remain committed to science, transparency, and patient-centred safety.

About the Author

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Tracy is an intensive care nurse and systems thinker with lived experience of hypermobile Ehlers-Danlos syndrome (hEDS), dysautonomia, and mast cell activation. She is the founder of **ConnectED Health**, an initiative combining clinical research, patient insight, and AI technology to improve diagnosis and care for complex, multisystemic conditions. Tracy works collaboratively with researchers and clinicians to bridge the gap between emerging science and real-world patient care.