

Case study: CSU #5

Initial Presentation and Diagnosis

The participant first noticed symptoms in the form of small, itchy red bumps initially mistaken for bed bug bites while staying at their parents' house. Over the course of a day, the number of bumps increased significantly, becoming very itchy. Upon visiting a doctor, the rash was clinically diagnosed as hives. The participant was prescribed Prednisolone with the hope of clearing the symptoms. Initial diagnosis was largely clinical, based on visual examination. After about six weeks, further blood tests were conducted, including thyroid function tests, which showed no abnormalities. The participant has a family history of autoimmune disease, though not specifically chronic urticaria. The diagnosis was considered spontaneous chronic urticaria related to an autoimmune origin.

"I had these little bumps that came up and I thought maybe it was bed bugs... one like those well, start out with two little red marks... then the next day I had probably about 10 and they were very itchy."

"I do have a family history of autoimmune disease... so it was likely a spontaneous chronic urticaria."

Treatment Journey

At diagnosis, the participant was prescribed multiple courses of antihistamines and Prednisolone, but these treatments proved ineffective in controlling symptoms. Difficulty accessing specialist care was a barrier; after persistent symptoms and repeated requests, the participant was fast-tracked into immunology via emergency presentation at a private hospital.

The immunologist introduced newer treatment options, including Montelukast and later Xolair (omalizumab), an immune-targeting therapy for chronic hives. The participant conducted independent research and was involved in treatment discussions but noted no prior discussions about genetic testing or biomarkers. Throughout the treatment journey, the participant's primary goal was not cure but achieving manageable symptoms to maintain quality of life.

"They weren't dulling the effects of the hives at all, and I was kind of left in the lurch with these spots all over me and nothing was working."

Ongoing Management and Prognosis

Currently, the participant experiences chronic urticaria with symptom severity fluctuating over time. They noted a reduction in symptoms during pregnancy but occasional flare-ups postpartum and while breastfeeding, suggesting a potential hormonal influence.

Ongoing management is coordinated through a public immunology clinic and the participant's GP. There is no single primary doctor; rather, care is provided by whichever immunologist is available via a general inquiry system. This arrangement has been in place for approximately nine months. The participant remains on daily medication to control symptoms and avoid worsening.

"I don't really have one doctor, it's just the doctors that are working in immunology... whoever is available will contact me."

Psychosocial Impact and Lifestyle Changes

The participant reported significant impact from the unpredictability and severity of hives. Dietary changes, such as adopting a whole foods diet and temporarily going vegan, have helped reduce flare-ups. They have identified possible food intolerances triggering symptoms but have yet to complete a formal food elimination diet due to ongoing breastfeeding.

The participant has prioritised their own health alongside that of their children, impacting treatment choices. Fear of long-term side effects from immunosuppressants has influenced decisions, particularly in relation to pregnancy and childbearing plans.

Health System Interactions and Experiences

The participant initially accessed care privately but transitioned to public specialist services for better ongoing access. Communication with immunologists is often via email, and they appreciate the ability to contact specialists as needed. However, there is no consistent single provider, and care is somewhat fragmented.

Allied health support has included dietitian consultations, which were valuable in identifying dietary triggers. There has been no participation in clinical trials or discussions about emerging therapies beyond standard options.

“I begged and pleaded to get into an immunologist... my GP suggested a shortcut... emergency department at a private hospital.”

Conclusions and Key Learnings

- This participant’s experience highlights the unpredictable and chronic nature of spontaneous urticaria, including the challenges of delayed specialist access and the limitations of standard antihistamine and steroid treatments. Their case emphasises the importance of patient advocacy in navigating health systems to obtain appropriate care.
- Hormonal factors such as pregnancy and breastfeeding appear to influence symptom severity, suggesting an avenue for further clinical inquiry.
- Dietary management, though informal and patient-driven, has shown benefit and should be supported by clinical nutrition guidance.
- Patients prioritise treatment approaches that minimise long-term harm and support family planning, underscoring the need for personalised, holistic care models.