MAST CELL ACTION

Lily Mason's Story

Lily is our beautiful 15-year-old daughter. She is determined, hardworking and innately kind. She has suffered chronic multi-system symptoms since birth and has previously lived on a diet of just 2 foods.

Every aspect of Lily's life has to be planned from food to potential triggers everywhere she goes. Lily has Mast Cell Activation Syndrome (MCAS).

When she was 6, her Paediatric Allergist described her as his most complex case. Whilst MCAS symptoms are complex there are many common and repeated patterns that are well documented in the literature.

> **"As a new born, Lily was sick after every feed, screamed a lot and seemed to be in pain. As she grew older, she developed a mouth full of ulcers, regular nausea and vomiting while eating, tummy aches and diarrhoea."**

When Lily was around the age of 2, we removed dairy from her diet under the care of a dietician. Although Lily improved a little, she was still not well. The dietician had Lily checked for coeliac disease and we removed gluten from her diet. However, things did not improve, and blood tests for IgE allergies came back negative. We kept a food diary, which revealed that Lily was reacting to egg. If accidentally exposed to eggs she would get hives and flushing.

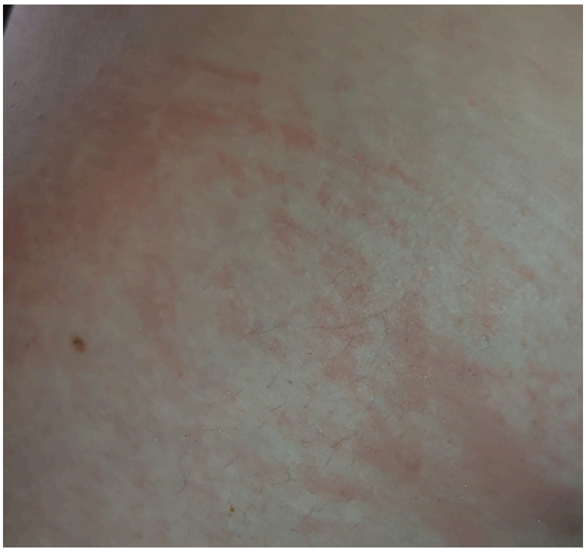
Over the next few years we knew something was not right. While Lily improved on her egg- and dairy-free diet, she was still not having formed stools and was going to the toilet up to 7–8 times a day. This made us sure something else was causing Lily to have gastrointestinal symptoms.

We were also concerned that Lily was always tired and had very dark circles under her eyes, as well as constant tummy aches and regular nausea. She had a reduced appetite and had episodes of blood in her stools and black tarry sticky stools.

When she was nearly 6 we were referred to a Paediatric Gastroenterologist, who agreed that something was not right. He undertook a colonoscopy and endoscopy in January 2016, and the results ruled out IBD, Crohn's disease and colitis. The Gastroenterologist suggested that Lily had the hydrogen breath test for fructose malabsorption and lactose intolerance, both were positive.

As Lily continued to be ill, with vulvodynia, headaches and throat swelling, we trialled a fructose-free and low FODMAP diet, eventually removing salicylates under the care of a dietitian.

> **"Lily is often too tired and poorly to live life as a normal 15-year-old and struggles with day-to-day activities."**



Many of Lily's symptoms went away or lessened – for example, her back pain, leg pain, blocked ears, nasal congestion, diarrhoea and hives all reduced, and she felt much better in herself. She looked healthier than she had in years.

However, Lily was still not 100% well and her episodic reactions were still increasing in severity.

Lily was already dairy, egg, fructose and sucrose-free, low-FODMAP and avoiding salicylates, but was still reacting. This is when we began to look into Lily's environment and it became more evident that Lily was reacting to various environmental triggers.

In November 2016, her consultant prescribed Nalcrom, which made a significant difference – in fact, Lily was totally well for the first time ever. He also prescribed fexofenadine but Lily had a severe reaction to it, and this reaction alongside a food trial caused Lily to become unstable again.

In March 2017, after testing positive for elevated prostaglandins in a 24-hr urine test, Lily was diagnosed with MCAS.

It took us many years to realise that Lily has reactions to environmental triggers, such as sudden temperature changes, as well as emotions like getting angry or anxious.

Despite taking high doses of a large number of medications, Lily now experiences severe flare-ups which are disabling and prevent her from being able to do many things which she loves - sometimes even meaning that she is unable to leave the house.

She has reactions to food, fragrances, cleaning products, pressure, weather, clothing - restricting what she can wear, to stress, hormones and even to her own hair touching her skin.

Lily's brother has since been diagnosed with MCAS after also exhibiting similar symptoms and testing positive for elevated prostaglandins in a 24-hr urine test.

“Our whole family life revolves around Lily's condition and every decision we make weighs up the risk to Lily”

Lily can no longer go into shops with fragranced products. We can't book a holiday, stay with family or go to busy places where there will be lots of strong perfumes, vapes or cleaning products – there is even something at the hospital that makes Lily unwell.

Raised awareness and guidelines for UK doctors, and ultimately a UK centre with a focus on this disease, would dramatically increase the quality of treatment and prevent costly and ineffective tests and consultations. There is an opportunity for the NHS to save money and deliver more effective treatment while improving the support and care available for those like Lily.