

A CASE STUDY:

WHEN LUPUS CAUSES

KIDNEY FAILURE

## A UNIQUE CLINIC AT CHILDREN'S HOSPITAL OF PHILADELPHIA OFFERS COLLABORATIVE CARE FOR LUPUS PATIENTS WITH RENAL INVOLVEMENT

N.S. was a healthy 14-year-old teenager who had traveled from another country to study English in New Jersey when she suddenly started having fevers. At a local emergency department she was found to have low blood counts that were attributed to a viral infection. However, she developed worsening fatigue, myalgias, and swelling of her legs and face. Two months later, she was hospitalized with widespread edema. She was found to have severe glomerulonephritis on a kidney biopsy and ultimately diagnosed with systemic lupus erythematosus.

Despite starting standard treatments for lupus, her kidneys quickly began to fail and her blood counts became dangerously low. She also developed a life-threatening bloodstream infection and began requiring additional respiratory support. She became increasingly scared and sad. She was transferred to the Children's Hospital of Philadelphia (CHOP) for further treatment in the Pediatric Intensive Care Unit (PICU).

At CHOP, her complex medical issues were co-managed by multiple subspecialists in addition to the PICU team. Nephrologists started her on dialysis temporarily because her kidneys were not making any urine. The rheumatologists managed the delicate balance of immune suppression to control the organ-damaging inflammation from her lupus, while the infectious disease experts oversaw the treatment and prevention of infections that are an unfortunate yet common side effect of immune-suppressing medications. Frequent team meetings were held to discuss her care, and included additional input from providers in the Lupus Program. Throughout everything, N.S. and her Spanish-speaking parents received continuous support from the Lupus Program's social worker to help them navigate the complexity of the healthcare system, and from a behavioral health specialist to support her emotionally through her critical illness. Her kidneys recovered and the swelling improved. She was able to be discharged and continued her follow-up care in the Lupus Integrated Nephritis Clinic (LINC).

*continued >*



### A clinic born out of specific needs

N.S. is one of approximately two dozen patients cared for in LINC, CHOP's multidisciplinary care clinic for youth with lupus who have renal involvement. Patients with lupus often need to see many different subspecialists, and LINC was established in 2018 based on the need identified by providers, patients and caregivers for streamlined, collaborative care. LINC eliminates the need for separate appointments in Rheumatology and Nephrology and enhances coordination among a team of lupus experts. The clinic also has a dedicated social worker and psychologist to integrate psychosocial care into routine visits and address the significant emotional needs of youth with lupus and their caregivers.

LINC is part of the Lupus Program, which is a larger effort to promote ideal health of youth living with lupus through innovative, high-quality care delivery models.

### Unraveling complex cases

Each case of lupus is unique. For each person affected, symptoms develop at different rates, with different levels of severity. CHOP has the expertise and experience to deal with complex cases involving medically fragile children like N.S. Clinicians in the Lupus Program use technological tools in the electronic medical record system that were designed specifically for the care of youth with lupus. The tools allow clinicians to track the disease path of each patient, including what areas of the body are affected, what symptoms are evident, and which treatments appear most effective. This information is shared with patients and caregivers during the visits to help personalize each treatment, but it also allows clinicians to spot any trends involving multiple patients. The clinical team's performance is also monitored to ensure that the care delivered is of the highest quality. This includes attention to the prevention of long-term complications of lupus so that youth like N.S. can continue living well with lupus into adulthood.

#### **PARTNER WITH US**

To refer a patient or request  
a second opinion:  
267-426-6298  
[CHOPUSA@email.chop.edu](mailto:CHOPUSA@email.chop.edu)

#### **LEARN MORE**

[chop.edu/linc](http://chop.edu/linc)