At 17, Kelsey Larson can’t remember life without psoriasis. Diagnosed when she was 4, she tried a spectrum of medications over the years, from topical steroids to ultraviolet light therapy to a now-banned treatment called Skin Cap. Nothing worked.

When Kelsey was 14, three dermatologists recommended the biologic drug etanercept (brand name Enbrel). Though approved to treat adults with moderate to severe psoriasis, Enbrel is not approved to treat children under 18 who have psoriasis. However, doctors often prescribe it “off label” for children on a case-by-case basis.

While she waited for approval to take the drug, Kelsey experienced one of her worst outbreaks. As a high school freshman and an avid dancer, she was devastated. “I had lesions on about 60 percent of my body and was in constant pain. It felt as though my skin was on fire.”

Kelsey’s dermatologist worked with her health insurance company to approve the biologic. The doctor discussed potential risks, but, says Kelsey, “I wasn’t really concerned with them because I wanted something that would work.”

Kelsey and her parents, Leslie Watkins and Doug Larson, say they carefully weighed the drug’s risks and benefits. They knew that the FDA had approved Enbrel for children with rheumatoid arthritis. “We could see the toll the psoriasis was taking on Kelsey, and we had a child who needed treatment immediately,” Leslie says. “We made the best decision we could to take care of our child.”

To her amazement, Kelsey’s face was beginning to clear up less than two weeks after her first injection. “And, I could see skin emerging from the psoriasis that covered my abdomen.”

Kelsey testified at a summer 2008 U.S. Food and Drug Administration (FDA) advisory committee hearing, advocating the use of etanercept to treat moderate to severe psoriasis in children ages 4-17. The committee unanimously recommended FDA approval of the drug. Kelsey’s testimony was instrumental in that decision.

Today Kelsey is dancing again. She attended her junior prom. “Without the medication I’m on now, I would not have been so confident. I didn’t have to worry that my itchy skin would bleed or that I would have to clean up the dry flakes from my skin.”

An FDA decision on the use of etanercept in children is pending. Meanwhile, Kelsey continues to advocate with her members of Congress for initiatives that ensure everyone has access to treatments that will improve their quality of life.