



**VIA ELECTRONIC DELIVERY**

**Date:** April 19, 2023

Donna Pickett, MPH, RHIA, Co-Chairperson  
ICD-10-CM/PCS Coordination and Maintenance Committee  
Classifications and Public Health Data Standards  
National Center for Health Statistics (NCHS)  
Centers for Disease Control and Prevention (CDC)  
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via email to: [nchsicd10CM@cdc.gov](mailto:nchsicd10CM@cdc.gov) and [tfr4@cdc.gov](mailto:tfr4@cdc.gov)

**RE: Letter of support for new ICD-10-CM code proposal L66.12 Frontal Fibrosing Alopecia (FFA)**

Dear ICD-10-CM/PCS Coordination and Maintenance Committee:

The Dermatology Nurses' Association (DNA) is a professional nursing organization comprised of diverse individuals who are committed to quality dermatologic care to provide exceptional patient outcomes through sharing knowledge and expertise. Our organization was incorporated in 1983 and our membership consists of over 1300 NPs, RNs, LPNs, MAs, Office staff, Doctors, and PAs who are involved and promote healthy dermatologic care to patients. Some of the DNA goals include Public Awareness & Advocacy; Education; Professionalism; Providing Benefits, Programs, & Services including community outreach; and Engagement, all of which to benefit our members and patients.

FFA is a primary cicatricial (scarring) alopecia that results in band-like hair loss in the front of the scalp. Concomitant loss of eyelashes, eyebrows, beard, and body hair occurs in many patients. Inflammation around the hair follicle causes fibrosis and permanent hair loss. Some patients also experience pain, itching stinging, burning, and crawling sensations on the scalp.

The cause of FFA is unknown but thought to be an autoimmune disorder influenced by genetic and environmental factors. Patients with FFA can experience significant distress from the disfigurement accompanying widespread scalp, face, and body hair loss as well as associated scalp pain. FFA has a distinct clinical presentation and is thought to have a unique pathogenesis from other forms of scarring hair loss.

Since originally described in case reports in 1994, the incidence of FFA has increased exponentially across the globe at an alarming rate. The absence of a designated code for FFA hinders patient care and research. The Dermatology Nurses' Association strongly supports the creation of a new ICD-10-CM code that differentiates FFA from other types of scarring alopecia.

The actual incidence and prevalence of FFA in the United States is unknown because there is not an ICD-10-CM code for FFA, preventing researchers from analyzing these cases in national data banks. There is not an FDA approved treatment for FFA. Efforts to develop new treatments are hindered by limited data due to inadequate ICD-10-CM codes.

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The DNA is optimistic that a new FFA code has the potential to improve data quality, facilitate adherence to clinical management guidelines, track patient outcomes, evaluate symptom progression, perform population-based epidemiological studies, and identify co-morbid conditions.

In summary, The DNA strongly supports ICD-10-CM code proposal **L66.12 Frontal Fibrosing Alopecia, FFA**. Adoption of this code has the potential to significantly improve patient care.

Sincerely,

The Dermatology Nurses' Association