

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)
3311 Toledo Road, Room 2402
Hyattsville, MD 20782
via email to: nchsicd10CM@cdc.gov and tfr4@cdc.gov

RE: Letter of support for new ICD-10-CM code proposal L66.81 Central Centrifugal Cicatricial Alopecia (CCCA)

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.

The DNA is writing in strong support of the proposal by the Scarring Alopecia Foundation (SAF) and the American Academy of Dermatology/Association (AAD/A) to create a new ICD-10-CM code for Central Centrifugal Cicatricial Alopecia (CCCA), **L66.81 Central Centrifugal Cicatricial Alopecia, CCCA**.

CCCA is a debilitating primary cicatricial (scarring) alopecia that disproportionately affects women of African descent, resulting in permanent and irreversible damage to hair follicles. Despite the significant impact on patients' quality of life, there is a lack of population studies on the true prevalence of CCCA, and its etiology remains unclear. While some studies suggest a genetic component, further research is needed to fully understand the disease's mechanisms.

Clinically, CCCA manifests as patches of permanent hair loss on the vertex or crown of the scalp and spreads centrifugally. Symptoms accompanying individuals with CCCA may include itching, burning, redness, and pain of the scalp. In addition to the signs and symptoms, it has been shown that individuals with CCCA may experience decreased quality of life and psychosocial distress because of the change in appearance and symptoms.

DERMATOLOGY NURSES' ASSOCIATION

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The DNA concurs with the importance of a new ICD-10-CM code that differentiates CCCA from other types of scarring alopecia and supports the creation of such a code. The current ICD-10-CM coding for CCCA fails to adequately capture the current and ongoing clinical understanding of CCCA. A specific ICD-10-CM code for CCCA would be a momentous step forward for the study of this *unique* disease. This new code will improve the granularity of data collection, facilitate adherence to clinical management guidelines, track patient outcomes, evaluate symptom progression, determine the prevalence of CCCA and any associated co-morbidities, and contribute to health policy decision-making.

In summary, The DNA fully endorses the proposal to create a new ICD-10-CM code for **L66.81 Central Centrifugal Cicatricial Alopecia, CCCA**. A specific and unique ICD-10 CM code for CCCA will advance patient care by facilitating access and consistency of treatment across different clinical specialists with the hope that this will play a role in significantly improving the lives of individuals with CCCA. Thank you sincerely for considering this matter.

Sincerely,

The Dermatology Nurses' Association