Hailey- Hailey Disease.com

Hailey-Hailey Disease Society

FEIN: 20-4174843
515 Park St, Harrison, MI 48625
989-539-0706
info@haileyhailey.com

Dear Health Care Professional:

I have HHD: Hailey-Hailey Disease.

Although sometimes called Chronic Benign Familial Pemphigus, HHD is NOT an autoimmune disease. There is a cell-cell detachment that resembles the process seen in true pemphigus, but there is no autoantibody causing the blisters. The detachment is found at the cell level and is exacerbated by friction and sweat. Loss of one functional copy of the gene coding for the protein SPCA1 (ATP2C1) causes HHD. This protein functions in the Golgi apparatus of keratinocytes to transport calcium and manganese ions. The gene has been mapped to chromosome 3, specifically 3q22.1. See OMIM #169600 and 604384.

In simpler terms, my skin is extremely fragile and prone to blistering and/or pulling apart, especially in intertriginous areas. Sweat and stress both exacerbate my disorder and I am prone to secondary infections that complicate healing. My condition is not contagious.

Please keep me dry and comfortable. Do not use adhesive bandages unless absolutely necessary. If you do use them, they will need to be soaked off or gently rolled off with mineral oil. If I am hospitalized during a major breakout, a private room and/or protective isolation techniques may be needed to keep me from developing a nosocomial infection.

I have listed my medications below.

You can learn more about my condition by visiting www.haileyhailey.com

Medication	How often used: