

Hailey Hailey Disease.com

Hailey-Hailey Disease Society

A 501(c)(3) Nonprofit Corporation

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Letter from the President:

Our first year has been a rewarding one! The First Annual Meeting brought the forming of the Board of Directors and the passing of the Bylaws. Memberships continued to come in throughout the months, and now include 25 members. The website is fully funded and new "Vanilla" forum software was brought online due to spam problems in the software provided by the hosting company. Most folks looking for support continue to join the TalkHHD Yahoo group. We are proud to announce that membership in this group has grown from 244 to 337 members in the last year, an increase of 38%!

The mission of the HHD Society is to provide correct information and support, so one of our projects is an informational brochure for patients and their families. The preliminary groundwork on this brochure has begun. We will need volunteers to help edit and proofread this document.

Helping HHD patients inform their healthcare team on their condition is another of our missions. We have placed a letter on Society letterhead for HHD patients to use with their healthcare provider on the TalkHHD website, and it has been well received. We will format this into a secure .pdf file and place it on the HHD website for easy access.

Another of our missions is to build a resource library. We would like to have a copy of each of the periodical references that we list on the website; we will need to have a copy of each of the references we use in our printed literature. These reference materials cost about \$10.00 each. Currently we only have enough funds to print and distribute about 1000 brochures and fund the website for about 4 years.

As the internet has become more easily accessible worldwide, it is our main focus and greatest achievement. In just the last year the website has had over 85,000 unique visits and served up over 2 million pages of information. In the last months, efforts have gone into making required changes to receive HONCode compliance certification. You can see our newly received certification and verify our compliance from our home page at: <http://www.haileyhailey.com>. We have been in contact with the British Association of Dermatologists and they have updated their website to include our site as a source of information and support for patients. We also receive and respond to requests for information periodically from patients and their physicians that are not answered by the website.

We look forward to another productive year and want to thank all of our members and donors for their past and continued generous support – without each of you we could not accomplish so much!

Jules McNaughton, CLS, MT(ASCP)
President, Hailey-Hailey Disease Society