

# Women's Survey Results Help Us Understand Female-Specific Issues

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The results are in! The NFED sponsored a survey to further characterize female-specific issues and their possible connection to Ectodermal Dysplasias.

## Background

Seventy-nine female respondents affected by Ectodermal Dysplasias completed a pilot survey about topics ranging from breast development and function, to menstruation and puberty. This survey laid the groundwork to verify that breast and vaginal concerns are associated with Ectodermal Dysplasias. A larger, follow-up survey provided results which fostered the growing correlation between these characteristics and Ectodermal Dysplasias.

Of the 2,333 surveys sent, 427 women between the ages of 12 and 83 responded. These women had many different diagnoses of Ectodermal Dysplasias, but the majority (118 women) were Hypohidrotic Ectodermal Dysplasia (HED) or HED carriers (159 women). Here is what we learned with their help.

## Sweating

Fifty-five percent of all respondents reported decreased sweating, while 35% had normal or excessive sweating. Ten percent claimed to have no sweating at all.

Sixty-four percent of women with HED also reported having decreased sweating. Twenty-one percent had no sweating at all, and 15% had normal to excessive sweating.

## Puberty

Fifty-two percent of the women reported having their first menstrual period at age 12 or 13. Both women with HED and HED carriers reported that they had their first period between the ages of 11 and 14. The majority (73%) of the total group reported that their regular cycles last between 4 to 7 days.

## Breast Issues

Twenty-five percent of the total group have one or both of their nipples that were either absent or hypoplastic, or, in other words, abnormally small.

At close to 30%, the majority of those surveyed with HED also reported having underdevelopment or incomplete development of nipples. Other issues included no breast development on either the left or right side, or no breast development on both sides. A small percentage also reported to either having no right or no left nipple.

HED carriers had a smaller percentage of reported breast issues. The biggest concern at 5% was that there had been no breast development on either their right or their left side. Less than 1% reported the absence of a nipple.

## Breastfeeding

One of the predominant concerns was breastfeeding. While 76.2% of the total group *wanted* to breastfeed, only 31.4% were successful. Almost half of the women needed to supplement breastfeeding with formula.

## Pubic Hair

Twenty-three percent of the total group has absent or sparse pubic hair, while 40% reported absent or

sparse axillary, or armpit, hair.

A more significant number of women with HED reported having this problem. Eighty-five percent reported sparse or thin head hair, while 64% said they had absent or thinning axillary hair.

For HED carriers, the majority at 66% claimed to have sparse, absent, or thin head hair. Forty-four percent said they experienced sparse, or thin pubic hair and 51% reported having these symptoms with their axillary hair.

### **Vaginal Issues**

Unlike the commonly reported breast abnormalities, there was not a large reported increase of abnormal uterus or vagina development as compared to the general population.

A troubling characteristic that is shared among these women affected by Ectodermal Dysplasias, however, is the reported percentages of those who stated intercourse was often painful. Eighty-five percent of the total group of 18 to 40-year-olds reported this as well as 100% of the women who were 41 years and older. Forty percent of HED women reported chronically painful intercourse.

Yeast infections also seemed to be prevalent in these surveys. Sixty-two percent reported them as a frequent occurrence. The majority of the women who reported this as a recurrent problem were 41 years and older.

14.5% reported having reoccurring bladder infections. Frequent, nighttime, or painful urination was also reported as well as urinary incontinence. These results, however, are not increased above general population rates.

### **Infertility (only reported for women with HED)...**

The majority of the women with HED reported having no problems with conception. Only 5% of the 18 to 40-year-olds reported having difficulty, while 21% of women older than 41 reported having previous difficulty.