Scarred for Life: Living with hidradenitis suppurativa (HS)

Hidradenitis suppurativa is a devastating condition affecting up to 4% of North Americans, and characterized by recurrent boils in the folds of skin, resulting in unpleasant odor and discharge.

Survey Sample
- 167 surveys from individuals with HS
- 30% from Canada and United States
- 96% female
- Average age: 36 years

Long Diagnosis Journey
- 62% of HS patients had more than 7 family physician visits before diagnosis
- 30% of HS patients had more than 10 medical emergency room visits before diagnosis
- Average time for diagnosis: 9 years
- Average age at diagnosis: 32 years
- Average referral wait time for dermatologist: 180 days

Misdiagnosis is Common
- 8/10 individuals had at least 1 misdiagnosis for HS

HS sufferers are dissatisfied with pre-diagnosis care
- 53% Strongly dissatisfied
- 18% Dissatisfied
- 16% Satisfied
- 10% Strongly satisfied
- 2% Unsure

Main HS Care Providers: Family Physicians & Dermatologists
- Dermatologist
- Surgeon
- Family physician
- Home care
- Dietician
- Nurse
- Endocrinologist
- Gynecologist

MOSH treatments are minimally effective
- 20% said surgical treatment provided significant improvement of HS symptoms
- 18% said dietary and lifestyle regimens provided significant improvement of HS symptoms
- Less than 30% have tried biologics, oral retinoids and corticosteroids for HS

HS impacts quality of life
- 70% Top 3 areas of struggle: Disease awareness, Depression, Hiding symptoms
- 91% HS negatively affects my work/school life
- 97% HS negatively affects my relationships
- Less than 1/10 patients received counselling from their healthcare provider for HS
- 9/10 HS patients rely on online support groups for HS information

HS patients are in pain
- 70% of respondents had severe pain

Living with HS is time-consuming
- Attending medical appointments: 65.5 average minutes per month
- Researching HS information: 300
- Wound care: 300
- Shopping for HS products: 120
- Participating in patient support groups: 300

Recommendations
- Increase HS awareness for healthcare providers.
- Evaluate HS patients for depression and offer support.
- Integrate a pain management discussion.
- Develop a coordinated multi-disciplinary approach for managing HS.
- Expedite funding decisions for new effective treatments of HS.

“I’m embarrassed all the time and can’t even tell friends or family because of the shame. Even though I know it’s not a hygiene issue, I think most people think it is. It’s humiliating. Please find a cure.”

Hidradenitis Suppurativa Patient Experience (HSPE) Survey results:
www.canadianskin.ca/hsreport