Ceri Harris
A Patients Perspective
Shall I tell you a story?

- Who am I and when did I first discover I had HS?
- How was I diagnosed and is this unusual?
- How has HS impacted on my life?
What do patients with HS want?

A Cure

Or

understanding
The Highs and Low’s of having an incurable condition.

High’s
- Getting to share information and support others
- Having a high pain threshold

Low’s
- Having a high pain threshold
- Having to explain what HS and watch the disgust on people faces
- Judgement of clinicians who think it’s just down to hygiene or weight
- Planning your clothing to hide stains
- Pain
- Hating your scars and limitations on your body
Barriers when dealing with Clinicians

- Lack of knowledge
- Assumptions
- Fear and self loathing
- Access to clinicians
- Access to treatment other than hibiscrub!
- Lack of Physical Support groups - safe places to meet others with HS
- Apathy within the HS community
What’s in our future?

- More opportunities to raise awareness with clinicians and the public
- Need for high profile coverage - removing the stigma
- Improved access to treatments
- More research into the causes and treatments
- A cure?
Thank you for letting me talk about my HS.