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 its 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

