

## Quality of Life in PHACE

Anita Hagstrom, MD  
Associate Professor, Dermatology and  
Pediatrics  
Indiana University

## Overview

- Quality of Life Measures
  - General
  - Hemangioma-specific
- Parental and family issues during infancy
- Considerations during childhood
- Resources



## Peer support

- AAD Camp Discovery Camps (MN, PA, TX, CT, WA)
- Skin Disease Foundation Camp Wonder
- About FACE

## Patient Advocacy/Support Groups

- PHACE Syndrome Community  
[phacesyndromecommunity.org](http://phacesyndromecommunity.org)
- Vascular Birthmarks Foundation  
<https://birthmark.org/>
- National Organization for Vascular Birthmarks  
<http://www.novanews.org/>