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TSC Alliance Webinar: Caring For a Loved One With Facial Angiofibroma Associated With TSC



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Welcome

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- Please speak with your doctor with questions about your medical condition.
- This webinar is being recorded.



Introduction and Background

Practitioner and Parent

Heather Harden, ACNP, FNP-BC

- My education
- My family
- My daughter

“I do not work in the TSC world as a practitioner, but I live in it as a parent”





Our Diagnosis Story



A Long Wait

First clues

- Initial concerns
- “Mother’s Instinct” – why I thought TSC
 - What we researched
 - Who we spoke with
 - What we didn’t know yet



A Long Wait (cont'd)

Tests, time, and impact of TSC Alliance

- TESTS that helped determine diagnosis: MRIs, EKGs, etc
- TIME needed to help figure out which characteristics to pay attention to:
 - Seizures
 - Heart issues
 - Angiomyolipoma (AML) near eye
 - Other organ issues
- TSC Alliance involvement

“The TSC Alliance helped us confirm my daughter’s diagnosis”



Treatments and Resources

Constant Communication with the Care Team



What we learned about treatment options and available resources

- Benefits of being treated at a TSC Clinic
- Treatment options we used
 - The importance of treatment frequency
- Our Care Team
 - Different doctors, different roles
 - Importance of dermatologists
- Learning on the fly
 - How/where we educated ourselves
 - What would the future look like?
 - What were our options?



Living with Facial Angiofibroma associated with TSC



A “Normal” Life

How we manage day-to-day life

- Mild facial angiofibroma characteristics compared to other cases
- Value of establishing normalcy in school and social surroundings
- Carrying around medication
- How we talk about facial angiofibroma and TSC with school, friends, family



Preparing for the Unknown

Always a potential for clinical changes associated with TSC

- Seizures
- Skin lesions
- Other concerns

Where we turn to prepare for the future

- Doctors
- Friends and family
- Resources online
- TSC Community





The TSC Community



The Value of Connections

Why talking to other parents and children is so crucial

- Friendships we've made
- How it helps our daughter
- How we stay involved with the TSC Alliance

“My experience as a parent has proven way more valuable than any knowledge or background as a practitioner”

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Q & A



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Thank You!