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

Eric J. Beresford, PharmD, BCMAS
VP – Medical Affairs, Nobelpharma America, LLC

Contact Medical Affairs with questions: 240-856-2127
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• The content herein and discussed during the webinar is for educational purposes only. This presentation is not intended to promote or encourage the prescription of any drug or treatment option and is not intended to be a substitute for professional medical advice, diagnosis, or treatment.

• 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”
Q & A
Thank You!