

# **Building and Sustaining a Camp for Youth with SB: What it takes to imagine a camp, bring it to life, nurture its growth, and ensure it thrives for years to come**

- Facilitator: Christine Murphy, M.D., FAAP -- Scottish Rite for Children; Camp TLC
- Panelists: Robin Lee, Executive Director, SBA North Texas; Julie Carter; Program Director, Camp TLC; Elissa Casey, OTR, ATP, Scottish Rite for Children

Panel Presentation for SBA Clinical Care Conference  
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# The Dream



# What Is Camp TLC?

- 6-day residential camp for children ages 9–16 with Spina Bifida and neural tube defects
- Hosted at Camp John Marc — a fully accessible, state-of-the-art therapeutic facility near Meridian, TX
- 90–100 campers each June with medical support from Scottish Rite, Children's Medical Center Dallas, and Cook Children's Hospital
- Activities include swimming, horseback riding, canoeing, rock climbing, archery, arts & crafts, and more
- Staffed by 2 directors, counselors, >15 nurses, 2 doctors, therapists, and Camp John Marc trained staff



# Camp John Mark



SEGMENT 1

# From dream to reality - Every year

Robin • 15 Minutes

*The timeline and recruitment strategy needed before the buses ever roll.*





# Funding & Partnership

## Camp John Marc

State-of-the-art accessible facility in Meridian, TX — purpose-built for special needs groups with trained staff

## SBANT Chapter

Handles financial logistics, fundraising, and administrative coordination for the camp program

## Medical Partners

Scottish Rite, Children's Medical Center Dallas, and Cook Children's Hospital provide clinical support



# Tour Bus





# Setting the Culture Early

**This is a true summer camp, not a medical retreat.**

- Set messaging during recruitment so volunteers understand the energy required
- Camp culture prioritizes fun, friendship, and independence
- Medical care is essential but invisible — kids should feel like campers first
- Campers come off the bus exhausted, full of stories, and already asking about next year

*"They understand each other's needs and abilities — many rarely see another individual with Spina Bifida except at camp."*

SEGMENT 2

# Bringing it to life - Every June

Julie • 15 Minutes

*Deconstructing the daily schedule, communication flow, and staff hierarchy.*



# The "Work Around" Philosophy

Activity times are sacred play times.

- Daily routines bend around the fun — not the other way around
- Medical care, meals, and logistics are scheduled to minimize disruption to activities
- Campers experience camp the way any able-bodied kid would
- Staff works behind the scenes to make the magic seamless

# Fostering Autonomy

## The Squad

- Older campers who've graduated to greater independence
- Manage their own care routines
- Sleep in cabins to help mentor younger campers
- Bridge between camper and junior leader

## Mentor Program

- Experienced campers paired with newcomers
- Teach self-care skills by example
- Build confidence through peer support
- Transition from reliant to independent



SEGMENT 3

# More than surviving - Thriving!

Elissa • 15 Minutes

*Safely adapting a rugged environment while pushing campers toward independence.*





# Adaptive Safety Protocols

## Closed-Toed Shoes

Mandatory at all times — no sandals ever, no exceptions

## Metal Wheelchairs

Keep out of direct sun — metal heats dangerously in Texas summer, and wet chairs cause wounds

## Overheating Watch

Recognize red faces from medication side effects — proactive cooling or activity switch

## SEGMENT 4

# Accidents will Happen!

Medical Director • 15 Minutes

*Medical logistics from screening campers to running the Med Shed.*

# Tour Bus



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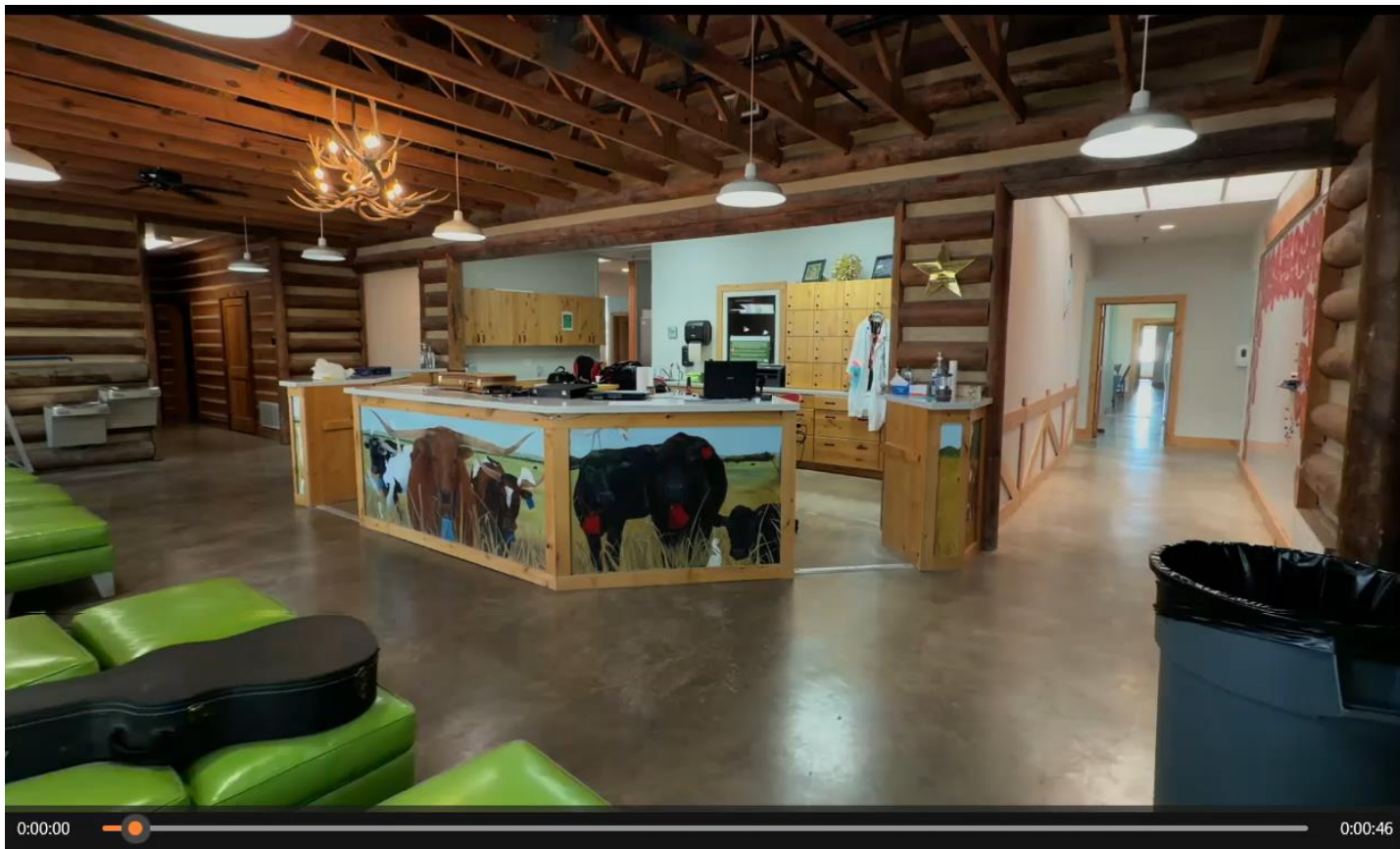
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# Designing the Med Shed

- ER Bay — for emergencies and acute care needs
- Private treatment sides — for caths, bowel programs, and wound care
- Med Shed is off-limits for casual hangouts — it's a working clinical space
- Central hub that serves 80–100 campers (and some counselors) across the week





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# Panel Q&A

*"When I'm at camp, I feel like I don't have to be alone all the time because everybody knows what you're going through and... every single thing is made for you so that you can do everything that you ever wanted to but in a special way".*

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