

# 2017 Annual SMA Conference, Disney World, Orlando, FL

## Wednesday, June 28<sup>th</sup>

3:00pm – 7:30pm                      Registration Open for all Conference Attendees                      West Registration

## Thursday, June 29<sup>th</sup>

7:30am – 5:30pm                      Registration Open for all Conference Attendees                      West Registration

11:30am – 4:15pm                      Newly Diagnosed Children’s Program                      Sorcerers Apprentice Ballroom

12:00pm – 4:00pm                      Newly Diagnosed Program                      Fantasia Ballroom G  
**(For Newly Diagnosed Families Only)**

12:00pm – 1:15pm                      **Introduction to Cure SMA and the Community**

**Parent Welcome**

**Understanding the Genetics and Disease**

**Understanding Treatment and Trials**

1:15pm – 2:45pm                      **Newly Diagnosed Breakouts**                      Fantasia Ballroom D-F, Fantasia Ballroom G, Pastoral 1  
**Session A – Type I – Optimal Care for SMA**                      Fantasia Ballroom D-F

**Session B – Type II/III – Optimal Care for SMA**                      Fantasia Ballroom G

**Session C – Grief and Loss (Support Session)**                      Pastoral 1

2:45pm – 3:15pm                      **Life After Diagnosis – Parents Share Their Journey**                      Fantasia Ballroom G

3:15pm – 4:00 pm                      Newly Diagnosed Meet & Mingle Reception                      Fantasia Ballroom A , B & C

5:30pm – 8:30pm                      Meet & Greet                      Fantasia Ballroom  
Includes Researcher Relay Race, games, Disney Characters

7:30pm – 10:00pm                      Teen Social                      Fantasia Ballroom E & F

7:30pm – 10:00pm                      Adults with SMA Reception                      Fantasia Ballroom A, B, C & D

## Friday, June 30<sup>th</sup>

7:30am – 8:45am                      Family Breakfast with Symposium                      Fantasia Ballroom H & J

Sponsored by Avexis

7:30am – 5:30pm	Registration and Check-in	West Registration
7:30am – 5:30pm	Exhibitor Tables Open	Fantasia & Pastoral Lobby
9:00am – 12:30pm & 2:00pm – 5:15pm	Children’s Program	Sorcerers Apprentice Ballroom 1 & 2
9:00am – 12:30pm & 2:00pm – 5:15pm	Baby Room	Sorcerers Apprentice Ballroom 3
9:00am – 10:15am	General Session Opening Remarks	Fantasia Ballroom G
9:00am – 10:15am	<b>Sibling Talk it Out (Ages 12 to 17)</b>	Fantasia M & N
10:30am – 12:30pm	<b>Workshop Session #1</b>	
	<b>Sharing your Type I Experience</b>	Fantasia D, E & F
	<b>Sharing your Type II Experience</b>	Fantasia G
	<b>Sharing your Type III Experience</b>	Fantasia A, B & C
	<b>Adults with SMA – Roundtable</b>	Fantasia P & Q
	<b>Grandparents Talk it Out Type I</b>	Pastoral 1
	<b>Grandparents Talk it out Type II &amp; Type III</b>	Fantasia K & L
12:30pm – 2:00pm	Lunch Break	Fantasia Ballroom H & J
2:00pm – 3:30pm	<b>Workshop Session # 2</b>	
	<b>Yoga Therapy for Adults and Teens with SMA</b>	Fantasia A, B & C
	<b>Genetics and Reproductive Options for SMA Families</b>	Fantasia M & N
	<b>Finding Hope After Loss: The Grieving Process for Parents</b>	Pastoral 1
	<b>Making Choices to Optimize Care and Quality of Life</b>	Fantasia K & L
	<b>Laughter Yoga for Caregivers</b>	Fantasia P & Q
	<b>Getting the Most Out of What You Eat! Nutrition for Oral Feeders</b>	Fantasia D, E & F
	<b>Standing, Walking and Mobility: Decision Making and Options</b>	Fantasia G

**Aquatic Physical Therapy for Fun & Function, Children with Supported Head Control**  
Contemporary Feature Pool

3:45pm – 5:15pm

**Workshop Session # 3**

**Dad’s Time: A Workshop for Fathers Only – Type II & III** Fantasia G

**Dad’s Time: A Workshop for Fathers Only – Type I** Grand Republic Ballroom B

**Orthopedic Management** Fantasia A, B & C

**Medical Management of Adults and Teens with SMA** Fantasia P & Q

**Independent Living with SMA Panel – Tips & Tricks for Living with SMA** Fantasia M & N

**Healing the Grieving Heart – Part I** Pastoral 1

**Ethics and Realities in SMA Research and Emerging Therapies** Fantasia Ballroom D, E & F

**Aquatic Physical Therapy for Fun & Function, Children with Independent Head Control**  
Contemporary Feature Pool

7:00pm – 9:30pm

Family Friendly Researcher Poster Session Fantasia Ballroom G - Q

**Saturday, July 1st**

7:15am – 8:30am Breakfast Items Fantasia Ballroom H

7:30am – 3:30pm Registration and Check-in West Registration

7:30am – 3:30pm Exhibitor Tables Open Fantasia and Pastoral Lobby

8:15am – 12:15pm & 1:45pm – 3:30pm Children’s Program Sorcerers Apprentice Ballroom 1 & 2

8:15am – 12:15pm & 1:45pm – 3:30pm Baby Room Sorcerers Apprentice Ballroom 3

8:45am – 10:15am

**Workshop Session #4**

	<b>Personal Care Assistants—How to find, hire and manage your PCA’s</b>	Fantasia M & N
	<b>Family Readiness for Emergencies</b>	Fantasia K & L
	<b>“I Need to Cough”: Ways to Keep Your Lungs Clear</b>	Fantasia D, E & F
	<b>The Role of PT and OT in your Child’s Life – Being a part of a Therapy Team</b>	Fantasia G
	<b>ADA Rights</b>	Fantasia P & Q
	<b>Yoga Therapy</b>	Fantasia A, B & C
	<b>Healing the Grieving Heart – Now What? Part II</b>	Pastoral 1

8:45am – 10:15am      **Memory Boxes for Siblings: Creating a Lasting Treasure (for children only)**      Pastoral 2  
    Jennifer Lemisch, MA, ATR-BC, LPC

Mourning the loss of a brother or sister with SMA is ongoing and can be a difficult process. Expression through grief activities often assists in restoration and healing for those experiencing the loss. This workshop will provide bereaved siblings an opportunity to make a memory box that will support the memories of their sibling and also learn about other creative legacy ideas to do on their own.

10:30am – 12:00pm	<b>Workshop Session # 5</b>	
	<b>Keepsake Creation: Grieving Through Art</b>	Pastoral 2
	<b>Breathing Strong All Day Long</b>	Fantasia A, B & C
	<b>Life Care Planning</b>	Fantasia G
	<b>Driving and Community Mobility</b>	Fantasia L & K
	<b>Tube Feeding and SMA: Recommendations and Practices</b>	Fantasia D, E & F

**Writing our Stories: A Workshop for Parents**

Pastoral 1

**Finding a job, interviewing and how to ask for modifications panel**

Fantasia M & N

**Women's Health in SMA**

Fantasia P & Q

**Aquatic Physical Therapy for Fun & Function, Teens and Adults**

Contemporary Feature Pool

10:30am – 12:00pm

**Sibling Talk it Out (Ages 5 to 11)**

Pastoral 3

12:00pm – 1:30pm

Family Lunch with Symposium  
Sponsored by Biogen

Fantasia Ballroom H & J

1:30pm – 3:30pm

Researcher Q & A Session

Fantasia Ballroom G

5:00pm

Cure SMA Evening at the Park

Disney's Magic Kingdom Park

**Sunday, July 2nd**

7:30am – 8:45am

Family Breakfast and Newborn Screening Symposium

Fantasia Ballroom G & H

8:30am – 11:30am

Children's Program

Sorcerers Apprentice Ballroom 1 & 2

8:30am – 11:30am

Baby Room

Sorcerers Apprentice Ballroom 3

9:00am – 11:15am

It's a Wonderful Life/Closing General Session

Fantasia Ballroom J - Q