

# 2023 International SMA Patient Advocacy Group Meeting

Tuesday, June 27, 2023  
Yacht Club Convention Center  
Room Asbury A & B



Make today a  
breakthrough.

# AGENDA

## Breakfast

8:00 am - 9:00 am

## Welcome and Opening

9:00 am - 9:20 am

Kenneth Hobby - Cure SMA, USA

## SMA Europe Treatment Access Tools

9:20 am - 9:40 am

Nicole Gusset - SMA Europe

## Roche/Genentech Introduction

9:40 am - 9:45 am

## Care and Combination Treatment

9:45 am - 10:05 am

Mary Schroth, MD - Cure SMA, USA

## Novartis Gene Therapies Introduction

10:05 am - 10:10 am

## Break

10:10 am - 10:25 am

## Real World Evidence and APAC

10:25 am - 10:45 am

Julie Cini - Spinal Muscular Atrophy Australia, Advocacy Beyond Borders

## Biogen Introduction

10:45 am - 10:50 am

## Advocacy and Newborn Screening

10:50 am - 11:10 am

Maynard Friesz - Cure SMA, USA

## ALAME Coordination Across Countries, Groups, and Differences

11:10 am - 11:30 am

Maria Isabel Acevedo - SMA

Foundation Colombia

Vanina Sanchez - Latin America

SMA Alliance

## Challenges in Standards of Care and Access Wins

11:30 am - 11:50 am

Alpana Sharma - Cure SMA India

Moumita Ghosh - Cure SMA India

# SPECIAL THANK YOU TO OUR SPONSORS



# CELEBRATING & STRENGTHENING

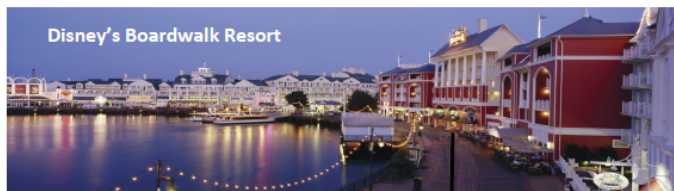
*community connections*



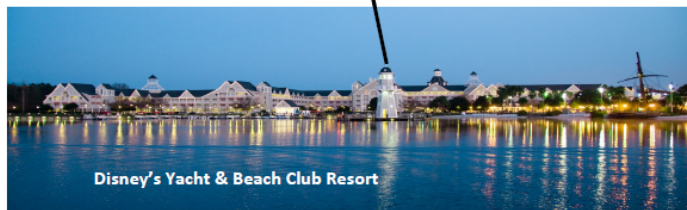
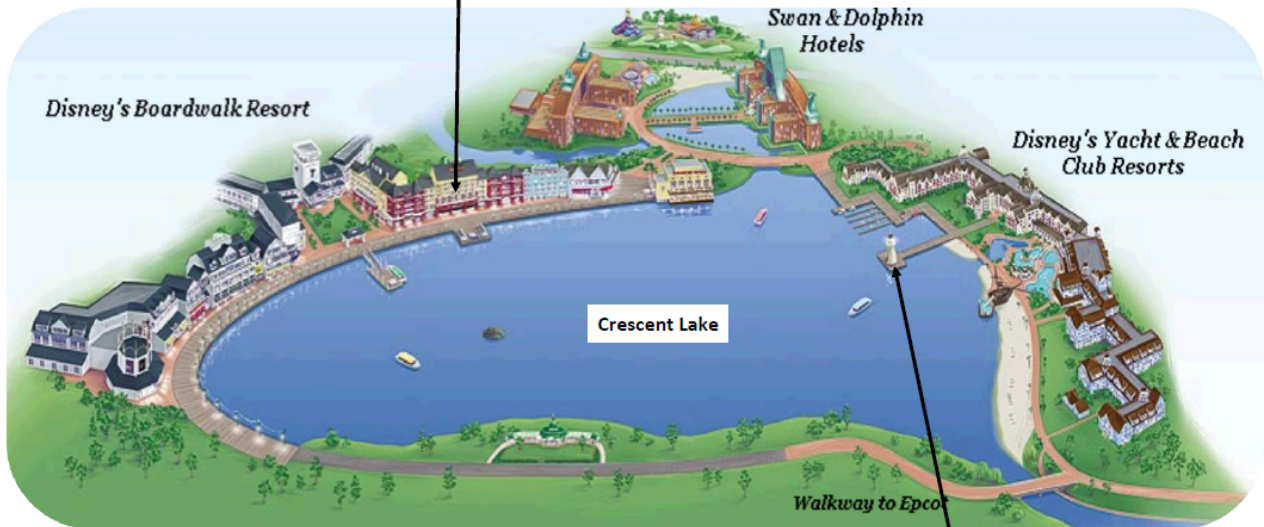
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Disney's Boardwalk Resort



Disney's Yacht & Beach Club Resort



## Together we are delivering

Together we are working to transform the treatment of rare diseases that were previously thought to be untreatable. For patients and families seeking information about rare diseases, gene therapy or clinical trials, educational resources from trusted organizations can provide a better understanding and help support discussions with your clinical team.

Visit [www.exploregenetherapy.com/gene-therapy-resources/helpful-links](http://www.exploregenetherapy.com/gene-therapy-resources/helpful-links) to learn more.

 **NOVARTIS** | Reimagining Medicine

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## Cure SMA Publications (available in 13 languages)

- <https://www.curesma.org/care-series-booklets/>
  - SMA Diagnosis From Newborn Screening – Family Guide
  - Understanding SMA
  - Genetics of SMA
  - Nutrition Basics
  - Caring for Emotional and Mental Health
  - Considering Drug Combinations
  - Health Insurance Roadmap
  - Living Unlimited: Newly Diagnosed
  - SMA Diagnosis From Newborn Screening – Healthcare Providers Guide

**cure  
SMA**



## Committed to the SMA community

We look forward to further collaboration with the SMA community at the 2023 International SMA Patient Advocacy Group and Annual SMA Conference. Biogen's commitment to the SMA community is steady and we continue to advance research on potential new treatment approaches for SMA.

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