

# SCHEDULE AT-A-GLANCE

July 27th- July 29th, 2018 Westin Austin Downtown Austin, Texas

### Registration

## Friday Scientific Forum

## Saturday Patient Forum

### Sunday

#### Westin Austin Downtown

310 E 5th Street Austin, Texas 78701 (512) 391-2333 westinaustindowntown.com

#### Registration/ Badge Pick Up Westin 3rd floor

Thursday 6:30 pm - 7:30 pm

#### Friday

7:30 am - 8:30 am 5:00 pm - 6:30 pm

For registration and hotel information.visit: creatineinfo.org/symposium

Meals are included in registration.

#### Breakfast

Fri./Sat. 7:30 am - 8:30 am

#### Lunch

Fri./Sat. See Schedule

#### Dinner

Fri./Sat. See Schedule

#### Kids Camp Provided by: KidSpark

#### Friday

8:30 am Drop-off 4:30 pm Pick-up

#### Saturday

8:30 am Drop-off 4:30 pm Pick-up

#### Ask the Experts Saturday

3:30 pm | Doctor Breakout Lounge 1:1 Q&A with SMAB

8:30 am - 8:45 am Introduction and Welcome

#### Session 1: Science of Creatine Metabolism

8:45 am - 9:15 am Physiology and Pathophysiology

9:15 am - 9:45 am CCDS Knockout Mice as a Model of Humans

9: 45 am - 10:15 am
Discoveries of CCDS Mice Models

10:15 am - 10:30 am Break

#### Session 2: CCDS Introduction and Indicators

10:30 am - 11:10 am Clinical Presentation

11:00 am - 11: 40 am Identifying Patients and Patient Challenges

11:40 am - 12:00 pm Brain Changes with MRI/MRS

12:00 pm - 1:30 pm Lunch

1:30 pm - 2:00 pm Seizures and Behavior

#### Session 3: CCDS Corrective Measures

2:00 pm - 2:30 pm Qualifying Newborn Screening

2:30 pm - 3:20 pm Novel Therapeutics CTD, AGAT | GAMT

3:20 pm - 3:45 pm

3:45 pm - 4:15 pm Investigational Treatments

4:15 pm - 4:30 pm Development of Consensus Guidelines for Treatments through Patient Registries and Natural History Studies

4:30 pm Open Panel Discussion

6:30 pm - 7:00 pm Cocktail Reception

7:00 pm-10:00 pm

8:30 am - 8:45 am Introduction and Welcome

8:45 am - 9:00 am The Role and Importance of Patient Advocacy Groups

9:00 am - 9:30 am A Deeper Understanding of CCDS

9:30 am - 10:00 am Current Therapeutics and Diet

10:00 am - 10:30 am Investigational Treatments for CCDS

> 10:30 am - 11:00 am Break

11:00 am - 11:30 am FDA and Drug Development

11:30 am - 12:00 pm Recognizing: Gene Sequencing and Gene Therapy

12:00 pm - 12:30 pm Symptom Management, Seizures

12:30 pm - 1:30 pm Lunch

1:30 pm - 2:00 pm Symptom Management, GI Issues

2:00 pm - 2:30 pm Assistive Technology: Speech and Language

2:30 pm - 3:00 pm Planning for the Future, Special Needs Trusts

3:00 pm - 3:15 pm Break

3:15 pm - 4:45 pm Applied Behavioral Analysis (ABA) Parent Training | Ballroom

> 4:45 pm - 5:00 pm Closing

> 6:30 pm - 7:00 pm Cocktail Reception

> 7:00 pm-10:00 pm

#### **Pool Time**

10:00 am - 12:00 pm

Let's Have fun!

Family time | Westin Pool Side Garden

Enjoy the rest of your stay in beautiful Austin, Texas

#### Featured Speakers Include:

Nicola Longo, MD, PhD Sarah Young, PhD, FACMG Andreas Schulze, MD, PhD, FRCPC Bruce Barshop, MD, PhD Kim Cecil, PhD Matthew Skelton, PhD Denise Morita, MD Yiumo Chan, PhD

Future speakers to be announced.

Conference hosted by:



Schedule subject to change.