

Hello CURE SMA Community,

What an incredible week it was during our time with you at the annual conference! Our hearts are full, and there is truly *nothing* that compares to the energy, resilience, and passion of this community.

We are deeply grateful for the time you shared with us, whether we caught up during a session, shared a conversation in the hallway, or listened to your powerful stories. Engaging with the CURE community always grounds us in why we do this work, and we came away deeply inspired and energized for the road ahead. In this month's edition, we're excited to share some of our favorite highlights and key takeaways from our time together.....

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Community Symposium!

We also hosted a lively, café-themed panel discussion titled "**Everyday Impact: Hear From Teenagers and Adults in the SMA Community.**" Led by Dr. Shade' Moody, Ambassadors: Shaniqua, Zack, and caregiver Keanna with her daughter Brooklyn, the session featured powerful personal stories about maintaining independence and daily routines.



Let's Keep Connecting!

If you missed us at the annual conference, don't worry! We have an incredible lineup of **Summit of Strength** events happening in cities all across the country throughout the rest of the year. Whether you are in Boston, Chicago, Portland, or beyond, these gatherings are the perfect environment to connect face-to-face, share stories, and build meaningful relationships with your local **Partnership and Access Liaisons (PALs)**



Can't make it to an in-person event? You can still stay fully plugged into the community from the comfort of your home! Mark your calendars for our next virtual educational program on **August 7, 2026**, titled "**Exploring Evrysdi (*risdiplam*).**" This session will feature **Dr. Shafeeq Ladha, MD**, Director of the Gregory W. Fulton ALS and Neuromuscular Disorders Clinic at the Barrow Neurological Institute, alongside community guests and ambassadors who will be sharing their personal experiences. Head over to **EvrysdiEvents.com** to register and save your spot!



Coming home from the conference and settling back into our daily routines, we want to ensure the incredible momentum we built together at the conference doesn't stop there. The stories shared, the connections made are what will carry us forward into the rest of the year. Thank you again to the entire CURE community for your unmatched energy, openness, and hospitality. We are already looking forward to our next opportunity to connect, collaborate, and continue changing lives together. Until next time!

We Might Be Coming to Your City Soon!

Missed the latest Summit? Don't worry! Keep an eye on the [CureSMA website](#) for details on upcoming city events and schedules! Whether you join us for a live program or participate in one of our [new, virtual events](#), we can't wait to see you there.

*The Genentech-hosted advocacy reception was a robust discussion highlighting the national and local policy and advocacy perspective shared by **Sarah Belish** and **Januel Gomez-Colon**.*

Core Discussion Themes

Advocacy Journeys

Sarah and Januel shared their personal paths to advocacy and its definition in the context of the SMA community.

Financial & Access Policy

A focus on systemic barriers, including Medicaid and SSI asset limits, the "*tax on caregiving*," and the "*Independence Agenda*."

National-Local Interplay

Analysis of how grassroots efforts (e.g., Rare Disease Advisory Councils) and national initiatives strengthen each other.



Future Advocacy

A look at the evolution of advocacy and actionable steps for community members to drive legislative change.

Thank you, **Sarah** and **Januel**!

"Thank you for sharing your stories and advocacy efforts with our community."

100+
ATTENDEES
at the reception

Step Back into the "Evryday Café" & Experience "Evryday Your Way"

Being together in the exhibit hall was such an energizing reminder of the unique spirit that makes this community so special. To celebrate that bond, our booth spaces were designed completely around you.

Take a look back at some of our favorite moments and highlights from an unforgettable week together



The Evryday Café

This accessible diner space brought our "Everywhere, Everyone, Everyday" values to life. Visitors loved connecting over the interactive menu, playing hands-free tunes on our custom **Jukebox**, and grabbing the fan-favorite **Sipping Sidekick** color-changing straws.

The Pinball Showdown

The centerpiece of the café was our fully adaptable pinball machine, created with Ambassador Zack. Its specialized, accessible controllers gave many players the chance to enjoy pinball.

Evryday Your Way

This dedicated activation space was all about celebrating adult community wisdom, independence, and perspective. It was incredible to see everyone coming together to discover and exchange creative daily life hacks, share their authentic experiences on navigating SMA in their own unique way, and encourage one another through the power of shared tips and stories.

If you don't know who your PAL is, you can find your local PAL or sign up on our website to get connected. PALs do not provide medical advice and are not a substitute for your medical team. Your healthcare provider should always be your main resource for any questions about your health and medical care.



Thank you for sharing the magic of Orlando with us! The conference was an incredible opportunity to connect, celebrate the SMA community, and create meaningful memories together.

Gina Truslow,
Director, Patient Advocacy Relations

**Please keep in mind that PALs are not part of your medical team, do not provide medical advice, and are not substitutes for your healthcare provider. Your healthcare provider should always be your main resource for any questions about your health and medical care.*

IMPORTANT SAFETY INFORMATION AND INDICATION

What is Evrysdi (risdiplam)?

Evrysdi is a prescription medicine used to treat spinal muscular atrophy (SMA) in children and adult.

- **Before taking Evrysdi, tell your healthcare provider about all of your medical conditions, including if you:**
 - are pregnant or plan to become pregnant, as Evrysdi may harm your unborn baby. Ask your healthcare provider for advice before taking this medicine are a woman who can become pregnant:
 - Before you start your treatment with Evrysdi, your healthcare provider may test you for pregnancy
 - Talk to your healthcare provider about birth control methods that may be right for you. Use birth control while on treatment and for at least 1 month after stopping Evrysdi
 - Pregnancy Registry. There is a pregnancy registry for women who take EVRYSdi during pregnancy. The purpose of this registry is to collect information about the health of the pregnant woman and her baby. If you are pregnant or become pregnant while receiving EVRYSdi, tell your healthcare provider right away. Talk to your healthcare provider about registering with the EVRYSdi pregnancy Registry. Your healthcare provider can enroll you in this registry or you can enroll by calling 1-833-760-1098 or visiting www.evrysdi-pregnancyregistry.com
 - are an adult male. Evrysdi may affect a man's ability to have children (fertility). Ask a healthcare provider for advice before taking this medicine
 - are breastfeeding or plan to breastfeed. It is not known if Evrysdi passes into breast milk and may harm your baby
- **Tell your healthcare provider about all the medicines you take**
- If you were prescribed Evrysdi for Oral Solution, you should receive Evrysdi from the pharmacy as a liquid. If the medicine in the bottle is a powder, **do not use it**. Contact your pharmacist for a replacement
- **Avoid getting Evrysdi on your skin or in your eyes. If Evrysdi gets on your skin, wash the area with soap and water. If Evrysdi gets in your eyes, rinse your eyes with water**
- **The most common side effects of Evrysdi include:**
 - For later-onset SMA:
 - fever
 - diarrhea
 - rash
 - For infantile-onset SMA:
 - fever
 - diarrhea
 - rash
 - runny nose, sneezing and sore throat (upper respiratory infection)
 - lung infection (lower respiratory infection)
 - constipation
 - vomiting
 - cough

These are not all of the possible side effects of Evrysdi. For more information on the risk and benefits profile of Evrysdi, ask your healthcare provider or pharmacist.

You may report side effects to the FDA at 1-800-FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at 1-888-835-2555.

Please see full **Prescribing Information** for additional Important Safety Information.