

# GENENTECH SMA COMMUNITY UPDATES | WINTER 2026

## Dear SMA Community,

We hope 2026 is off to an amazing start for you! Looking back, 2025 was a time that was undeniably defined as a year of great change. We successfully navigated shifts, adapted our strategies and embraced new opportunities to better serve YOU! However, the most important outcome of this transformation was the **unwavering commitment to make it a true year of connections**. The resilience and strength of the relationships we share with the SMA community is the enduring success story that will propel us forward. We look forward to continued partnership!

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## Evrysdi® (risdiplam) Tablet Updates



We are so excited to have launched the **Evrysdi® (risdiplam)** tablet formulation in 2025, which—alongside our oral solution—gives the community options for at-home treatment that offer a number of potential benefits:

- Evrysdi tablets can be stored at room temperature - no need for refrigeration. Evrysdi 5-mg tablets are approved for people aged 2 years and older who weigh at least 44 lb (20kg). The tablets cannot be taken with feeding tubes.
- Evrysdi tablets can be swallowed whole with water or as a mixture with non-chlorinated drinking water (eg, filtered water, bottled water)—whichever works best for you
- Each once-daily Evrysdi tablet already contains your dose, so there's no need for measuring
- Evrysdi tablets come in a 30-day supply so you need less frequent refills (hear more about how this has made an impact for SMA community member, Tilly, below)

We're also proud to share what we've seen so far in terms of insurance coverage for tablets - **in the 8 months since Evrysdi Oral 5 mg Tablet was launched in the US, we are seeing broad payer coverage with over 90% of eligible Commercial and Medicaid members covered.**



## Getting Ready for the New Year: Tips for a Smooth Start

January can bring changes to your insurance and coverage. A little preparation now can help your **Evrysdi** treatment continue without interruption.

- **Review your insurance:** Deductibles and out-of-pocket costs often reset in January. If your plan changes, let your provider and specialty pharmacy know right away.
- **Renew assistance programs:** Many copay or financial support programs require yearly re-enrollment—watch for renewal notices by mail or email.
- **Plan ahead for prescriptions:** Refill early and consider enrolling in digital tools (like app or text reminders) for easy management. Switching treatments may lead to insurance challenges; ensure you understand your coverage details before you and your doctor decide to switch.
- **Use your FSA funds:** Check eligible expenses, such as prescriptions or medical supplies, before your plan year ends.
- **Stay ahead of Medicaid changes for 2026:** Earlier this year, Congress passed sweeping changes to Medicaid and to the Affordable Care Act (ACA) exchanges via the One Big Beautiful Bill Act (also referred to as O3BA or HR 1), including new enrollment and community engagement requirements for Medicaid enrollees. Many policies set forth in the law do not take effect until December 2026 or later. There are actions you can take now to ensure you are prepared.
  1. **Affordable Care Act open enrollment runs through January 15, 2026** (or even later for certain states). Check your state website for enrollment deadlines.
  2. **Be extra vigilant when it comes to opening mail, reading emails, and screening phone calls.** This could be your insurer calling with information related to your coverage, plan, or renewal requirements.
  3. **Know the name of your insurer and plan.** If you are a Medicaid patient, for example, your state Medicaid agency may not have "Medicaid" in the name.



## Living with SMA can be a lot to manage—but you're not alone.

Don't forget that your **Genentech Partnership and Access Liaison (PAL)** can help with insurance, reauthorizations, and any other questions to keep your care on track!

And if you don't know who your PAL is, you can [find](#) your local PAL or [sign up here](#) 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.*



### Q&A with Tilly G. (Evrysdi Patient)

#### Q: How has your experience on Evrysdi tablet been so far?

**A:** “Moving from the liquid to the tablet has been such a positive change for me. One of the biggest benefits has been the flexibility in administration it’s given me in my daily life...I also love that I can just

put the tablet into my bag and take it wherever I am. Whether I’m working, out with friends, or traveling, it’s so much easier to stay consistent with my treatment. It’s a small change, but it has really helped me and I can keep up with everything that matters to me with less interruption.”

#### Q: What was your access journey to obtaining the medication like?

**A:** “Getting access to the tablet was actually a really smooth process for me. My healthcare team walked me through everything step by step and made sure I understood the transition. Once the prescription was approved, it was delivered from the pharmacy right to my home, and I could start right away. It honestly felt empowering to know there was an option that fit my lifestyle better, and one that made managing my treatment feel more seamless and less clinical.”

#### Q: What does the 30-day supply mean for you?

**A:** “Having a 30-day supply gives me such peace of mind. I don’t have to worry about running out or juggling multiple refills throughout the month — it just makes everything more predictable and less stressful. Knowing I have what I need for the month ahead lets me focus on my life and my work instead of constantly planning around my medication schedule.”



Genentech remains dedicated to the SMA community. We'll continue to champion the voices of patients and caregivers, as your lived experiences are invaluable to the future of our work.

Best wishes,

**Gina Truslow**, Director  
Patient Advocacy Relations

## IMPORTANT SAFETY INFORMATION AND INDICATION

### What is Evrysdi?

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

- 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.evrysdipregnancyregistry.com](http://www.evrysdipregnancyregistry.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
- 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](http://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.