



Dear families and friends,

What a whirlwind year it's been! From Terry's Foundation's rapid development to the early success of Sarepta's gene therapy, I believe we've started to see the tide begin to turn in this battle. Without a doubt though, there is a very long road ahead and we must keep pushing forward to keep success coming – Summit's failure with ezutromid (Utrophin) acts as a sobering reminder that all can be quickly lost. Below, you'll find our newsletter that talks about TFMD's efforts along with industry-wide developments. We hope you find it helpful.

All the best,
-Rich Horgan
Founder & President

Terry's Foundation Events

Our Duchenne Education Conference was held this past weekend. It was a great day filled with informative presentations and insightful questions. It was wonderful to see connections grow between families, industry experts, academic researchers and clinicians.



Terry's Foundation Annual Gala, October 19th, 2018

Join us for our second annual gala to help raise money for DMD research. This year, we will be hosting the gala at **Boston's Museum of Science on October 19, 2018 from 6:00-9:00PM**. The gala will feature dinner, an auction (including tickets to Hamilton here in Boston!) and a keynote address. Come join us for a fun evening overlooking the Charles! **Tickets include on-site parking and museum access!**

All proceeds raised will be directed to cutting-edge academic research.

For more details: <https://tfmd2018gala.eventbrite.com> (<https://tfmd2018gala.eventbrite.com>)



TFMD in the News

Check out this interview with our Founder, Rich Horgan, featured by the Boston Business Journal:

<https://www.bizjournals.com/boston/news/2018/06/22/inspired-by-family-a-new-duchenne-foundation-and.html>
(<https://www.bizjournals.com/boston/news/2018/06/22/inspired-by-family-a-new-duchenne-foundation-and.html>)

Created with Wix.com. Love It? [Try It! It's Free.](http://www.wix.com?referralInfo=SO_LP) (http://www.wix.com?referralInfo=SO_LP)

This past Wednesday ABC Boston (WCVB) ran a short clip on the foundation and what we are aiming to accomplish. You'll find the link to the short clip below:

<http://www.wcvb.com/article/5-for-good-brother-creates-foundation-for-sibling-with-muscular-dystrophy/21972268>
(<http://www.wcvb.com/article/5-for-good-brother-creates-foundation-for-sibling-with-muscular-dystrophy/21972268>)

TFMD Funded Research

Kunkel Lab

- Effort to accelerate early-stage therapeutic approach amenable to all forms of DMD. Six-month preliminary report expected in Q4 2018.

Boston Children's/UMass - Personalized Medicine

- Effort to use genomic sequencing and downstream analyses to enable personalized therapeutics development to treat rare DMD types. Preliminary report out due end of Q4 2018.

Industry News

- Sarepta Therapeutics Announces that at its First R&D Day, Jerry Mendell, M.D. Presented Positive Preliminary Results from the First Three Children Dosed in the Phase 1/2a Gene Therapy Micro-dystrophin Trial to Treat Patients with Duchenne Muscular Dystrophy

More Details Here (<http://investorrelations.sarepta.com/news-releases/news-release-details/sarepta-therapeutics-announces-its-first-rd-day-jerry-mendell-md>)

- Summit Therapeutics Announces PhaseOut DMD Did Not Meet Primary Endpoint

More Details Here (<http://www.utrophintrials.com/>)

- Solid Biosciences Announces FDA Removes Clinical Hold on SGT-001

More Details Here (<https://investors.solidbio.com/news-releases/news-release-details/solid-biosciences-announces-fda-removes-clinical-hold-sgt-001>)

- Sarepta Therapeutics Enters into Long-term Strategic Manufacturing Partnership with Brammer Bio to Support Gene Therapy Development and Commercial Supply

More Details Here (<http://investorrelations.sarepta.com/news-releases/news-release-details/sarepta-therapeutics-enters-long-term-strategic-manufacturing>)

Follow us:



www.facebook.com/TerrysFoundationforMD



www.instagram.com/terrystfoundationformd



www.linkedin.com/company/terry-s-foundation-for-muscular-dystrophy/



[@terrystfmd](https://twitter.com/terrystfmd)

Interested, or know of someone interested, in helping TFMD grow? Reach out to rich@terrystfoundationformd.org (mailto:rich@terrystfoundationformd.org)

Visit our Website  (<https://www.terrystfoundationformd.org/>)