

SAFE + EFFECTIVE = YES!

"The Race to Yes" provided a campaign platform to advocate for accelerated FDA approval of safe and effective therapies for children facing Duchenne Muscular Dystrophy, the number one genetic killer of children in the world. Children with Duchenne (1 out of 3,500 in the US) gradually lose muscle function and usually die by their early twenties. Founded in March 2014, The Race to Yes" advocacy campaign was sponsored by organizations pursuing Duchenne therapies including Charley's Fund and Team Joseph and the campaign ran until the FDA ultimately granted families accelerated approval to the therapy in 2016.



Goals:

- Immediately encourage the FDA to pursue accelerated approval of safe and effective therapies for Duchenne Muscular Dystrophy under Federal law passed by Congress.
- Gain awareness for Duchenne Muscular Dystrophy

Strategy:

Unify a dispersed group of individuals and organizations to form a credible, high profile, newsworthy national campaign platform that responsibly encouraged the FDA to say "yes" to new therapies using the White House petition portal as the focal point to acquire 100,000 online signatures within 30 days, thereby ensuring a White House and FDA response.

Tactics:

- Brand and build <u>www.theracetoyes.org</u> as the online platform and headquarters. Re-brand existing advocate sites and social media
- Mark the milestones of the campaign through a series of optimized press releases
- Employ social media to convey graphic memes, video updates, info-graphics, showcase celebrity support, and gain advocate feedback
- Recruit and activate volunteers through email campaigns and the establishment of "Team 100": those committed to actively pursue online petitions.
- Regular blog posts: http://theracetoyes.org/category/blog/
- Online "Town Hall Meeting"

Execution:

Given the urgency, the entire campaign was conceived and executed within two months, starting on April 9 at a hearing in Washington DC, a launch of the TheRacetoYes.Org and attending social media on March 1, 2014, and culminating in over 100,000 signatures gathered at the WhiteHouse.gov. A team of seven provided 18 hour per day coverage throughout the petition drive.

The petition gathering was completely organic, and fostered by recruiting advocates through email campaigns and social media. Less than \$500 was spent on Facebook advertising. Celebrity support came in the form of re-tweets came from Sarah Jessica Parker, The Altman Brothers Band, and Drew Carey. Media reports from around the country were documented on a YouTube video as encouragement that we would reach our goal.



Evaluation:

The campaign was measured a success by virtue of the following criteria:

- The campaign resulted in the largest hearing turnout in the history of the FDA and ultimately families were given accelerated approval to the therapies.
- 100,000 White House petition signatures in less than 30 days. See: <u>http://www.theracetoyespetition.org</u>
- The FDA Commissioner publically referred to the campaign as the "most intense" advocacy engagement she had ever seen.
- The Commissioner met with the CEO of the company that made the promising therapy and agreed to work with them toward the goal of accelerated approval
- The FDA response was featured on the front page of the *Washington Post* and the story credited The Race to Yes for the "relenting" on the part of the FDA
- Online coverage in over 60 top tier digital print and broadcast media outlets. See: <u>http://theracetoyes.org/news/</u>
- Campaign videos on YouTube received thousands of views
 - https://www.youtube.com/watch?v=M_W0gFvs4jc
 - o <u>http://youtu.be/DTZizFZOtQY</u>
 - http://youtu.be/VJikL6ze-WU
- 5000 organic likes on Facebook in 30 days
- 70+ participants in online "Town Hall" for volunteers



BY BRADY DENNIS

For much of last fall and winter and into this spring, scientists at the Food and Drug Administration wavered over what to do about a potential new drug to slow the progression of Duchenne muscular dystrophy, a devastating disease that overwhelmingly affects boys, leaving most in wheelchairs by their



onlin ing fi than White ers or to top face r On Sarep thous

Award and Reward

The campaign resulted in an FDA hearing (the largest in history) and accelerated approval for the therapy was ultimately granted. Click on the video below to view



The Race to Yes campaign is given a prestigious national award.

