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Dr. Jeffrey Chamberlain

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Riding for Dale, September 8, 2012, Knoxville, Tenn.

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Max Leclaire, 10, participates in the Sarepta trial.

CureDuchenne is pleased by [Sarepta Therapeutics](#) (formerly AVI BioPharma) announcement on July 24 that its exon-skipping compound, eteplirsen, achieved a significant clinical benefit in a Phase IIb trial in Duchenne patients. CureDuchenne, along with Children's National Medical Center in Washington, DC and the Foundation to Eradicate Duchenne, provided funding in 2010 for this research to progress into human clinical trials.

This is a milestone for the company and patients alike. It demonstrated for the first time that eteplirsen achieved a highly significant clinical benefit on the 6-minute walk test, over a placebo/delayed treatment cohort in a Phase IIb trial in DMD patients. Eteplirsen was administered once weekly at 50mg/kg over 36 weeks, and patients on treatment demonstrated a 69.4 meter benefit (227 feet benefit) compared to those who received placebo/delayed treatment. The drug was well tolerated; there were no treatment-related adverse events, no serious adverse events and no discontinuations.

The next milestone is at 48 weeks, and the data is expected in October. It will include analysis of dystrophin levels from muscle biopsies in addition to the clinical outcome measures. If it goes as planned, the result will pave the way for an end of phase II meeting between the company and the FDA to discuss and agree to the plan for a phase III registration trial.

"This is a good day for Duchenne, and I'd like to thank CureDuchenne for their support and funding as well as many other organizations and institutions that provided support over the last few years," said Chris Garabedian, CEO of Sarepta Therapeutics.

"Our family is so grateful to CureDuchenne for helping to fund this research which has given us hope for our two boys future, for the first time ever," said Jenn McNary, whose 10-year-old son Max is one of the boys enrolled in the Sarepta trial. "It is with tears in my eyes that I wish to thank CureDuchenne, Sarepta, Nationwide Children's Hospital research team and everyone else who is so dedicated to finding a cure."

According to Debra Miller, founder and CEO of CureDuchenne, "This is the news the Duchenne community has been waiting for; a safe and effective disease-modifying treatment is within our reach and it allows us to focus on the parallel development of next round of drugs that target the other exons. We must remain cautious since there is still a long way to prove this drug will provide significant benefits over time, many drugs fail to achieve FDA approval at this stage."

[Click here](#) to read the Sarepta Therapeutics press release.

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Join Ryan Getzlaf and Tee-Off at the Getzlaf Golf Shootout



Ryan Getzlaf, captain of the Anaheim Ducks, is hosting the 2nd annual Getzlaf Golf Shootout on September 8 and 9. This spectacular charity event will be held at the beautiful Monarch Beach Golf Links in Dana Point, Calif. A pre-golf dinner reception will be held at Sutra in Costa Mesa. Join gold medalist and NHL All-Star Ryan Getzlaf, along with Corey Perry and other Anaheim Ducks and Los Angeles Kings players; Kent French, the voice of the Ducks; actor Kevin Connolly; and other celebrities and community leaders to support CureDuchenne.

The Getzlaf Golf Shootout is an opportunity to interact with your favorite players, play golf and support a great cause. There is still time to buy tickets. Foursomes cost \$2,800 and include a celebrity or athlete as a fifth golfer plus eight tickets to the pre-golf dinner reception. Individual tickets are also for sale for \$700.

If you don't golf, you can still meet Getzlaf and support CureDuchenne by attending the reception on September 8. Tickets for the dinner are \$100. The evening will include food, drinks, a program and silent and live auction. Live auction items include: Ducks locker room experience; fly-fishing expedition for four at the Montana Sporting Club; a BeerMaster beer dinner for 10; and a Ferrari weekend experience.

"My wife, Paige, and I are happy to continue our support for CureDuchenne and their valued efforts in finding a cure for Duchenne," said Getzlaf. "Both Paige and I can't imagine what it would be like for our son to grow up and not to be able to walk, run or play sports. We want to provide help for many generations to come of Duchenne boys."

Please join Ryan and Paige, for a fun-filled weekend and support CureDuchenne. For more information and to register, [click here](#).

For sponsorship information, contact Debra Miller at 949-872-2552.

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Connor Pyle, 13, races to raise awareness and fund to find a cure for Duchenne.

Connor Pyle, 13, is racing in the Jack in the Box Summer Shootout Series to raise awareness and funds to find a cure for Duchenne muscular dystrophy. Connor's 5-year-old cousin, Chase, is living with Duchenne. A portion of his winnings, as well as any additional money he raises, benefits CureDuchenne.

Connor's orange and black Young Lions Legend Car features the CureDuchenne logo and a photo of Chase. Connor has signed autographs and participated in run-a-thons, slushie sales and interviews to help spread the word and raise money to find a cure for Duchenne.

[Click here](#) and [here](#) to read more about Connor's efforts to raise funds on behalf of CureDuchenne.



Connor Pyle's race car features his cousin, Chase, and the CureDuchenne logo.

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The 2nd Annual Knoxville Brewfest held on June 23 in downtown Knoxville, Tenn., raised \$27,000 to benefit CureDuchenne. This beer celebration featured two bands, 2,000 people and 200,000 ounces of craft beer.

The event was organized and directed by Martin Daniel, owner of Elevation Outdoor Advertising, and Chris Morton, owner of the Bearden Beer Market, to help raise money to find a cure for Duchenne. Daniel's 4-year-old son has Duchenne.

"The Knoxville Brewfest is a way to sample the finest beers around the region and country and have a great time while helping the 300,000 boys worldwide who have Duchenne," said Daniel.

"The funds raised by this event will support research projects that are so close to treatments to save our sons' lives," said Debra Miller, founder and CEO of CureDuchenne.

Knoxville Brewfest was presented by Bearden Beer Market. Tier One sponsors included: Smoky Mountain Brewery, Vic's Beer Store, Samuel Adams, New Belgium Brewing and Lamar Outdoor Advertising.



The sold-out Knoxville Brewfest is a huge success.



Martin Daniel (right) and friends enjoy the Knoxville Brewfest that benefited CureDuchenne.

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Thank you, Martin, for putting on another successful Knoxville Brewfest. CureDuchenne is grateful for your support.

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CureDuchenne wants to thank everyone who supported the 4th Annual Climb to CureDuchenne. We raised more than \$40,000 to help find a cure for Duchenne. Please enjoy the following two videos that feature the regional Climb to CureDuchenne events and the elite team's climb to Mt. Kilimanjaro. Thank you to everyone who participated or donated. We look forward to even more Climb to CureDuchenne teams from across the country next year.

[Climb to CureDuchenne video](#)

[Mt. Kilimanjaro video](#)

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Chelsea, Scott, Braedan and Tammy Henegar (left to right).

In many ways Braedan Henegar, 6, is a typical first-grade boy. He loves the outdoors, animals and enjoys playing with his family's four dogs. He is a Sprint Car Racing fan and enjoys going to the track to watch. Braedan is active and likes to swim, ride his bike and play t-ball.

What isn't so typical is that when Braedan turned 5 he was diagnosed with Duchenne. Now his parents have to balance his natural activeness with a new daily routine that involves living with the disease.

"I want him to be able to be an active boy and experience everything boys like to do, but we always have to be aware of what he is doing and think about if he is being too harsh on his muscles," said Tammy Henegar, Braedan's mom. "It is a huge struggle to have the right balance."

Braedan's routine has changed. It now includes daily stretches and physical and occupational therapy. The Henegar's watch what Braedan eats and limit his salt and sugar intake. Rather than going to the neighborhood school he goes to a school that is 15 miles away because it is all on one level.

Braedan knows that his muscles are different than other children. He tires out sooner and his muscles ache. He is starting to ask more questions.

"Right now Braedan is doing really well," said Henegar. "We will continue to stay up with the latest research and keep him as mobile as long as possible until there is a cure."

Henegar has been a big supporter of CureDuchenne and other Duchenne organizations. In April, she hosted a parent outreach session for more than 40 people in Perrysburg, Ohio. In July, Braedan participated in the Wooden Bat Tournament in Dayton that benefited CureDuchenne.

Braedan is a huge Clay Matthews fan, even before finding out the connection with CureDuchenne. Matthews, a linebacker for the Green Bay Packers, is a CureDuchenne spokesperson.

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“Even though we are taking this journey through life that we never thought we would be traveling down, it is bitter sweet,” said Henegar. “We are having new experiences and are meeting wonderful people such as everyone at CureDuchenne, and all the other families we have met and became close too. We’ll continue to work tirelessly to help raise awareness and funds to find a cure.”

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Dr. Jeffrey Chamberlain

Dr. Chamberlain is the director of a large research group centered in the Department of Neurology, University of Washington School of Medicine. He is also the McCaw Endowed Chair in Muscular Dystrophy at the University of Washington.



The Chamberlain laboratory is focused on understanding and developing treatments for the muscular dystrophies and other disorders of muscle. Their studies center on the Duchenne muscular dystrophy (DMD) gene (dystrophin), the loss of which is the causative factor behind the disease, and they are exploring the expression and function of this gene in addition to various shortened forms termed micro-proteins.

The lab focuses on three approaches:

- Studying the function of the proteins dystrophin and utrophin and how they interact with other proteins. They are developing shortened versions of dystrophin and utrophin that they call micro dystrophin and micro utrophin.
- The development of viral-derived shuttle vectors (a drug delivery mechanism) to deliver micro dystrophin and other genes to muscles for gene therapy. These vectors are being tested for safety and efficiency of delivery and also for their ability to halt or reverse the dystrophic phenotype in animal studies. The primary vectors being studied are derived from adeno-associated virus (AAV), which efficiently transfer genes to skeletal muscle and heart in mice and dog models. Methods are being refined for whole body systemic delivery.
- The use of muscle stem cells to treat Duchenne by replacing or regenerating muscle.

"We have made a lot of progress," said Dr. Chamberlain. "We are currently optimizing the micro-dystrophins we have developed and are testing them to learn which work best. We are also developing computer models to modify micro-dystrophin and utrophin in order to identify modified proteins that might be most effective in treating Duchenne and Becker muscular dystrophy."

When dystrophin is delivered in large quantities by this approach, it is possible that it may stimulate an immune response in the body. Consequently, the Chamberlain lab is focused on comparing utrophin with dystrophin, as utrophin delivery is not expected to cause an immune response.

"The approach we are taking is designed to target the fundamental cause of Duchenne and address the loss of the dystrophin protein; this approach is applicable to every DMD patient," said Dr. Chamberlain. "That being said, it is a difficult route and will take additional time in order to thoroughly test in the clinic as compared with anti-sense oligos."

CureDuchenne is considering whether to support Dr. Chamberlain's work and the lab is currently developing a grant to help move this research into human clinical trials.

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The Getzlaf Golf Shootout is a spectacular, two-day charity celebration held at the beautiful Monarch Beach Golf Links in Dana Point. Gold medalist and NHL All-Star Ryan Getzlaf, along with a host of other NHL stars, celebrities and community leaders, will come together in support of CureDuchenne. Foursomes cost \$2,800 and include a celebrity or athlete as a fifth golfer plus eight tickets to the pre-golf dinner reception.

The pre-golf dinner and live auction will be held on Saturday, September 8 from 5:30 p.m. 9:30 p.m. at Sutra in Costa Mesa. The golf tournament is Sunday, September 9 at Monarch Beach Golf Links in Dana Point. Registration is at 9 a.m., shotgun at 10:30 a.m. and the awards ceremony is at 4 p.m.

[Click here](#) to register.

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More than 150 riders will set out on a 100-mile motorcycle ride "Riding for Dale" through Knoxville, Tenn., on to Middlesboro and through the Smokey Mountains and ending at Old Town for a celebration party. The "Riding for Dale" event will benefit CureDuchenne.

The event is being coordinated by Heather Bayless, whose son Dale lives with Duchenne. For more information, contact Bayless at 865-585-5266.

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The 2012 Golf Ball Drop to Benefit Cure Duchenne and Almost Home Dog Rescue will take place on September 15 in Quakertown, Penn.

Numbered golf balls are being sold in advance for \$20 each. At 4 p.m. on September 15 a drop bag holding all 2,000 balls will be lifted into the air from the ladder of a fire truck, courtesy of Milford Square Fire Company & positioned over a hole in one. A cord at the bottom of the bag will be pulled allowing the balls to drop.

This is a chance for anyone in the Duchenne community to help the cause no matter where you live. If you are interested in selling or buying golf ball tickets, please contact Donna Doyle, through Facebook or donna@donnadoolittle.com.

Tickets will be mailed to you or people can pay through PayPal and you will be sent a virtual ticket. Go to PayPal.com, log-in and click "Send Money To" and put in this email address golfballdrop2012@yahoo.com. Choose "sending as gift" option so no money will be charged by PayPal. Put your name in the subject line so you get credit for it. The person who sells the most golf balls wins \$500.

- **First prize - \$4,000**
- **Second prize - \$1,000**
- **Third Prize - \$500**
- **Fourth through eighth prize - \$100 each**

The first ball that lands in or closest to the hole wins. Should there be more than one ball that is closest to the hole the prize will be shared.

The event will also include crafters/vendors, animal rescues, food & refreshments, live music, antique airplanes, airplane rides, games for the kids, raffle items, face painting and pumpkin decorating.



"Together we can CureDuchenne"

August 2012

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CureDuchenne is proud to be an official charity of the Tinker Bell Half Marathon. The Tinker Bell Half Marathon weekend is January 18-20, 2013.

Disneyland® Resort becomes Never Land for a magical weekend. It starts with a Family 5K and a Kids' Races and culminates with 13.1 mile run that weaves through Disneyland® Resort. To register for the CureDuchenne Crusaders team, please call CureDuchenne at 949-872-2552.



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Save the date for the Champions to CureDuchenne Newport Beach Gala on February 9, 2013 at the Balboa Bay Beach Club in Newport Beach, Calif.