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CUREDUCHENNE CARES

Phoenix CureDuchenne Cares Session Featured Aquatic Therapy,
**Research Update**

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**CureDuchenne Cares - Education And School Advocacy**

The CureDuchenne Cares Dallas session included guest speaker Tiffany Cook, a speech pathologist and parent of a teenager with Duchenne muscular dystrophy. She shares best practices on advocating for your child at school...

[Read more.](#)

**Physical Therapist Karin Gorman Is A Glimpse Of Hope For Local Duchenne Community**

After her 10-month-old nephew was diagnosed with Duchenne muscular dystrophy, Karin Gorman was inspired to learn more about the disease and find a way to make a difference in the lives of families and individuals affected by Duchenne...

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**NEWS**

**Eighth Annual Champions To CureDuchenne Gala Presented By Fired Up Charity Foundation**

Some champions are made on a field and some become champions by giving from the heart. On April 8, hundreds of champions committed to finding a cure for Duchenne muscular dystrophy will gather at The University of Texas Golf Club for the eighth annual Champions to CureDuchenne gala to raise awareness and help CureDuchenne find a cure for this fatal genetic disease...

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**Dear Mom And Dad Video**

Jack Wolf, a teenager impacted by Duchenne muscular dystrophy, writes a letter to his mom and dad about the challenges living with Duchenne. The video features his accomplishments and the challenges he faces...

[Read more.](#)
Take Action Californians

CureDuchenne is proud to sponsor SB 643. This bill will add Duchenne to the Genetically Handicapped Persons Program’s (GHPP) list of eligible medical conditions...

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RECENT SUCCESS

Napa In Newport Raises $1 Million To Help Find A Cure For Duchenne Muscular Dystrophy

More than 400 people gathered at the Ritz-Carlton on Saturday, March 4 to enjoy the nectar of top Napa Valley wineries and help find a cure for Duchenne muscular dystrophy...

Read more.

UPCOMING EVENTS

Champions To CureDuchenne, April 8, 2017, Austin, TX

Save the date for the Champions to CureDuchenne gala on April 8 at the University of Texas Golf Club. Join us for a magical evening to find a cure for Duchenne muscular dystrophy. The event includes cocktails, dinner, casino, live and silent auction...

Read more.

CureDuchenne Cares Workshop For Families, April 8, San Diego, CA

Please join CureDuchenne Cares for a free, informative class on Duchenne muscular dystrophy on April 8 in San Diego, CA for family members and caregivers at UC San Diego Medical Education and Telemedicine Building from 8:30 am to 2:00 pm...
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Read more.
PTC Therapeutics Announces Agreement To Acquire Emflaza™ For The Treatment Of Duchenne Muscular Dystrophy In U.S.

- Emflaza is the first treatment approved in the U.S. for DMD patients 5 years and older, regardless of genetic mutation
- Aligns with PTC's mission and commitment to the DMD community
- $140 million upfront consideration (comprised of cash and PTC common stock) plus potential contingent payments based on net sales and single milestone payment
- PTC to host investor conference call today, March 16, 2017 at 8:30 am ET

PTC Therapeutics, Inc. (NASDAQ: PTCT) announced on March 16 that it has entered into an asset purchase agreement with Marathon Pharmaceuticals, LLC to acquire all rights to Emflaza™ (deflazacort). Emflaza is the first treatment approved in the United States for all Duchenne muscular dystrophy (DMD) patients five years and older, regardless of their genetic mutation. DMD is a rare and fatal genetic disorder that results in progressive muscle weakness from early childhood and leads to premature death due to heart and respiratory failure. Emflaza aligns with PTC's mission to bring therapies to patients who have rare diseases with limited or no treatment options.

"With our nearly 20-year commitment to the Duchenne community, it is deeply meaningful for us to bring this critical therapy to U.S. patients," said Stuart W. Peltz, Ph.D., chief executive officer of PTC Therapeutics, Inc. "We believe Emflaza is a disease-modifying therapy that has been shown to slow disease progression. In keeping with PTC's mission, we are excited to work with the community to raise the standard of care for DMD patients."

DMD treatment guidelines recommend steroids as a foundational component of the standard of care. Emflaza reduces inflammation, which is critical to preserving muscle function and delaying disease progression. It received FDA approval on February 9, 2017 and has the potential to benefit many DMD patients in the U.S.

"Our goal has always been to ensure Emflaza is studied, understood and available to any Duchenne patient who needs it, and we determined that this transaction is the best path for ensuring that will happen," said Jeff Aronin, president and CEO, Marathon Pharmaceuticals, LLC. "Now that we have achieved FDA approval of Emflaza, the
focus can turn to ensuring patients have access to this important therapy. PTC is well known by the Duchenne community and is ideally positioned to achieve this shared goal."

"Based on our long-standing experience with DMD and strong partnership with the community, we believe PTC is uniquely positioned to launch Emflaza in the U.S.,” added Mark Rothera, PTC's chief commercial officer. "We are finalizing our commercialization plans and intend to share more information after the transaction closes."

Read more.
ReveraGen BioPharma Receives FDA Fast Track Designation For Vamorolone For The Treatment Of Duchenne Muscular Dystrophy

ReveraGen BioPharma Inc, a privately held corporation, announced on March 24 that the U.S. Food and Drug Administration (FDA) has granted Fast Track designation for vamorolone (VBP15) for the treatment of patients with Duchenne muscular dystrophy. This designation can speed the review of efficacy and safety data for vamorolone in boys with DMD, potentially leading to more rapid regulatory approval. Vamorolone is under parallel guidance from the FDA and the European Medicines Agency (EMA).

By granting this designation, FDA acknowledges that the vamorolone program is directed towards development of a potential treatment for a serious condition, and addresses an unmet medical need. The VISION-DMD clinical trial program for vamorolone is currently enrolling boys with DMD into clinical trials in US, Canada, Australia, Sweden, UK, and Israel (open label Phase 2a, Phase 2a extension, and Long-term extension studies). Blinded, placebo- and glucocorticoid-controlled Phase 2b trials are expected to initiate enrollment later this year.

“We are excited about this new development in our discussions with FDA”, said Eric Hoffman, Ph.D., CEO of ReveraGen. “We hope that our innovative clinical program in DMD, with extensive use of pharmacodynamic biomarkers, will lead to a rapid read-out of drug effect”.

About vamorolone

Vamorolone is an oral, once-daily formulation with multiple mechanisms of action that are thought to target multiple aspects of DMD muscle pathology. It is a potent glucocorticoid receptor agonist that shows strong anti-inflammatory activity, but without many of the safety concerns seen with other steroidal immune modulators. Vamorolone is also a mineralocorticoid receptor antagonist, and has been shown to aid dystrophic heart function in mouse models of DMD. Finally, vamorolone stabilizes plasma membranes, and may counteract the membrane instability caused by dystrophin deficiency in DMD. The vamorolone DMD clinical program is supported by the National Institutes of Health (NIAMS, NINDS) and the European Community Horizons 2020 program.

About ReveraGen BioPharma

ReveraGen is a privately held, clinical-stage pharmaceutical company with vamorolone in DMD as the lead program. The vamorolone pre-clinical and clinical programs have been carried out in collaboration with international stakeholder non-profit foundations and governments, and with Actelion Pharmaceuticals through an initial milestone payment related to an option agreement for future vamorolone sales and distribution.
PTC Therapeutics Announces FDA Acknowledgment Of New Drug Application Filing For Translarna™ For The Treatment Of Nonsense Mutation Duchenne Muscular Dystrophy

PTC Therapeutics, Inc. (NASDAQ: PTCT) announced on March 6 that the U.S. Food and Drug Administration (FDA) has acknowledged the filing over protest of PTC's New Drug Application (NDA) for Translarna™ (ataluren), an oral, first-in-class, protein restoration therapy for the treatment of nonsense mutation Duchenne muscular dystrophy (nmDMD). The Company is seeking approval to market the drug for the treatment of nmDMD patients in the United States. Translarna received marketing authorization for patients with nmDMD in the European Union in August 2014 and is now available in over 25 countries.

The FDA has granted standard review and assigned a Prescription Drug User Fee Act (PDUFA) date of October 24, 2017. The PDUFA date is the target date for the FDA to complete its review of the NDA.

"We look forward to working closely with the FDA and the DMD community to bring this much-needed therapy to patients," said Stuart W. Peltz, Ph.D., Chief Executive Officer, PTC Therapeutics, Inc. "We believe that the totality of clinical data in our NDA, which includes the results of two of the largest placebo-controlled DMD clinical trials ever conducted, demonstrates Translarna's benefits to patients and merits a full and fair review by the FDA, including an advisory committee meeting."

Primarily affecting males, Duchenne muscular dystrophy is a progressive muscle disorder caused by the lack of functional dystrophin protein. Dystrophin is critical to the structural stability of skeletal, diaphragm, and heart muscles. Patients with DMD lose the ability to walk in their early teens and experience life-threatening lung and heart complications in their late teens and twenties. It is estimated that nonsense mutations account for approximately 13% of DMD cases.

PTC used the FDA's file over protest regulations to file the NDA. These regulations allow a company to have its NDA filed and reviewed following receipt of a refuse to file determination.

Read more.
Phoenix CureDuchenne Cares Session Featured Aquatic Therapy, Research Update

On Saturday, February 25, 2017, CureDuchenne Cares held another successful Family Workshop in Phoenix, Arizona, at The Salvation Army Ray and Joan Kroc Corp Community Center. The event drew in families from surrounding cities in Arizona and Texas. There were more than 45 attendees, which included parents, grandparents, family members and friends of those with Duchenne muscular dystrophy, along with boys and young adults living with Duchenne themselves.

The daylong event began with a warm welcome by Debra Miller, Founder and CEO of CureDuchenne, who provided the history of the organization, how the CureDuchenne Cares program began, and how we are supported by our family network and industry partners. The attendees learned about physical therapy by CureDuchenne’s Director of Physical Therapy, Celeste Graham, and the latest in clinical trials and research by our Chief Scientific Advisor, Dr. Michael Kelly, PhD, along with representatives from sponsoring pharmaceutical and biotech companies.
CureDuchenne was very excited to introduce our new Community Engagement Manager, Kylee Groon! Kylee will play an integral role in helping families across the nation and beyond in connecting with each other, sharing valuable resources and supporting individualized fundraising efforts.

The Phoenix Family Workshop was also happy to include Dr. Jennifer “Jen” Weil, PT, MPT, DHSc—a local physical therapist with advanced training in aquatic therapy, myofascial release and cupping, and kinesiotaping interventions. Utilizing the Kroc Center’s onsite pool facilities, Jen and one of her clients did a live demonstration of aquatic therapy—an intervention that is beneficial for those living with Duchenne for low load exercise, stress relief on joints, sensory input, respiratory benefits, socialization and fun! The aquatic therapy demo was a unique addition to our typical workshop agenda.

A mother with a young son living with Duchenne said that she would recommend this workshop to others, as it provides “social” opportunities and a way to “connect with other families.”

The next Family Workshop is a partnership with the University of California-San Diego and will take place at UCSD on April 8, 2017. We will also be in Milwaukee on April 22. Join us for these free sessions.

Do you want CureDuchenne Cares to come to your city? Please contact Celeste@cureduchenne.org or 949-872-2552. Be sure to also check www.CureDuchenneCares.org often for updates on the 2017 sessions!

CureDuchenne Cares 2017 presenting sponsors are Sarepta Therapeutics and Marathon Pharmaceuticals. Other CureDuchenne Cares sponsors include PTC Therapeutics, Pfizer Inc and Bamboo Therapeutics, Santhera Pharmaceuticals, Invitae, and Summit Therapeutics.
The CureDuchenne Cares Dallas session included guest speaker Tiffany Cook, a speech pathologist and parent of a teenager with Duchenne muscular dystrophy. She shares best practices on advocating for your child at school.
After her 10-month-old nephew was diagnosed with Duchenne muscular dystrophy, Karin Gorman was inspired to learn more about the disease and find a way to make a difference in the lives of families and individuals affected by Duchenne.

A fatal genetic disease with no cure, Duchenne muscular dystrophy causes muscle deterioration and affects more than 300,000 boys worldwide. There are currently only two FDA-approved pharmaceutical treatments and one helps only a limited number of Duchenne patients. As patients grow older, they typically lose their ability to walk by 12 years old and have an average life expectancy of mid 20s. Physical therapy is the only non-pharmaceutical treatment that has a positive impact on most patients as they combat Duchenne.

Karin has been a physical therapist for eight years and received her PT education from Creighton University in Omaha, NE. She currently practices in Phoenix. It was immediately after her first pediatric rotation that she realized she wanted to dedicate herself to helping children. She now works at a school helping children with special needs. After finding out her nephew was diagnosed with Duchenne, she wanted to find a way to combine her existing skills with advanced education to help, what she feels, is an underserved community.

"After my nephew was diagnosed with Duchenne, I was compelled to pursue the CureDuchenne Cares certification to not only help him, but an entire community of families and individuals with Duchenne. With this certification, I hope to be a valuable resource and positive advocate for proper treatment for those affected by Duchenne," explains Karin.

As a physical therapist, Karin has taken numerous continuing education courses that help her review and refine her skills to make her patients with other childhood disorders stronger. Due to the deteriorating factors of Duchenne, the physical therapy goal is to maintain mobility and motor skills for as long as possible. Even then, at a certain point, the disease takes over. Karin attended the CureDuchenne Cares Certification Program to help explore the world of physical therapy as it applies to Duchenne.
Eighth Annual Champions To CureDuchenne Gala Presented By Fired Up Charity Foundation

To Be Held April 8 at The University of Texas Golf Club

Some champions are made on a field and some become champions by giving from the heart. On April 8, hundreds of champions committed to finding a cure for Duchenne muscular dystrophy will gather at The University of Texas Golf Club for the eighth annual Champions to CureDuchenne gala to raise awareness and help CureDuchenne find a cure for this fatal genetic disease. Champions for CureDuchenne is hosted by Quan Cosby, former wide receiver from UT, and presented by the Fired Up Charity Foundation. Tickets for this Texas-sized unforgettable evening are $150 and the event will be emceed by Jim Spencer, chief meteorologist at KXAN-TV.

Found mostly in boys, Duchenne muscular dystrophy causes muscle degeneration, growing worse as patients get older. Those with Duchenne often lose their ability to walk by their mid-teens and the disease claims their lives by their mid-20s. Duchenne affects one in 3,500 boys in the U.S. There are limited treatment options, and there is no cure for Duchenne muscular dystrophy.

Eight years ago, former University of Texas coach Mack Brown and his wife Sally teamed up with Tim and Laura Revell, parents of two boys with Duchenne muscular dystrophy, and created Champions to CureDuchenne, the Longhorn-style party held annually at the University of Texas Golf Club. Through the ongoing commitment of many throughout the community, Champions to CureDuchenne has raised more than a million dollars towards finding a cure for this devastating disease.

“When our sons were first diagnosed, there was little hope for children with Duchenne muscular dystrophy,” said Tim Revell, parent of two boys with Duchenne. “In the last year, we’ve seen two treatments approved, but this is not a cure. Boys with Duchenne continue to have their lives cut short way too soon, and by coming together as a community, we can change that. CureDuchenne needs your support to further invest in the thousands of boys whose lives are affected by Duchene. We need more champions to help us find a cure.”

The Champions to CureDuchenne Austin Gala is presented by Fired Up Charity Foundation. Event sponsors include Designer Floors of Texas, Fitzpatrick Insurance Solutions, H-E-B Tournament of Champions, NFL Alumni Austin,
Reese Family Foundation, Russell Korman, Sarepta Therapeutics, Small Luxury Hotels of the World, Summit Stoneworks, and Waypoint Lighting. The event will feature cocktails, dinner, casino, silent and live auction. To purchase tickets and for more information, please go to www.ChampionsforaCure.org.
Dear Mom and Dad Video

Dear Mom and Dad

Jack Wolf, a teenager impacted by Duchenne muscular dystrophy, writes a letter to his mom and dad about the challenges living with Duchenne. The video features his accomplishments and the challenges he faces. Jack shares his gratitude to his parents for all their support through his journey with Duchenne. For more information about Duchenne, please go to www.CureDuchenne.org.
CureDuchenne is proud to sponsor SB 643. This bill will add Duchenne to the Genetically Handicapped Persons Program’s (GHPP) list of eligible medical conditions.

Patients with Duchenne currently receive specialized coordinated care through the California Children Services program (CCS), a state program that serves children with rare, complex health care needs. When they age out of the CCS system at 21 years of age, their families are left to navigate a healthcare system that provides very little specialized care and support.

The GHPP is a state health care program for adults with certain genetic diseases. The GHPP provides complete coordinated services to its clients by working closely with doctors, nurses, pharmacists, and other members of the health care team. Adding Duchenne to the GHPP list of eligible conditions will improve continuity of care for patients in California.

For more information on how you can take action, contact Kylee@cureduchenne.org
Leader In Cure, Care And Community For Duchenne Muscular Dystrophy CureDuchenne Launches New Website

CureDuchenne, the leading nonprofit focused on finding a cure for Duchenne muscular dystrophy, launched a new website at www.CureDuchenne.org to further reflect its mission which focuses on improving and extending the lives of all those with Duchenne.

Duchenne muscular dystrophy is a fatal genetic disorder that causes muscle degeneration and typically effects boys. Currently there are nearly 15,000 boys in the U.S. battling this disease and 300,000 worldwide. Most boys with Duchenne lose their ability to walk by age 12 and do not survive beyond their mid-20s. As the disease progresses, the simplest of tasks become difficult, and in the later stages, heart and breathing muscles begin to fail. At this time, there is no cure for Duchenne.

"CureDuchenne continues to accelerate the cure, redefine care and build a community for all those impacted by Duchenne," said Debra Miller, founder and CEO of CureDuchenne. “We are dedicated to finding a cure for this devastating disease. We hope that with the help of the new website, individuals will be able to learn more about Duchenne and take action to help find a cure."

The new website provides resources and information on three core areas:

- **Cure**: With a goal of finding a cure for all genetic mutations of Duchenne, CureDuchenne is focused on funding the most promising and qualified preclinical and clinical research to save lives.

- **Care**: There are limited treatment options for Duchenne patients, and CureDuchenne provides a vital education resource for parents, caregivers and clinicians in order to help ensure loved ones have the best care.

- **Community**: CureDuchenne brings together families, caregivers and medical professionals to share experiences, advice, and personal stories, giving hope and support to the entire community.

The updated website allows viewers to find Duchenne-related resources ranging from research overviews to family stories about those affected with Duchenne. The website also includes information on free upcoming CureDuchenne Cares workshops; clinical trial information; fact sheets and infographics about Duchenne; details on exon skipping; Duchenne care topics such as physical therapy; and more.

The website comes at a pivotal time in continuing CureDuchenne’s progress towards finding a cure. This past year has been a victorious one in many ways, with the approval of the first ever drug to treat Duchenne; though Exondys51 is only effective for 13% of the Duchenne population, it’s a big step in the right direction. Another drug EMFLAZA, a steroid, was also approved for all boys with Duchenne.

CureDuchenne’s research portfolio is also highlighted on the new website in the **CureDuchenne Ventures** section. It
includes 12 wide-ranging projects to help treat the whole disease. This pipeline of therapies comes from a diverse array of cutting edge technologies used to treat all aspects of Duchenne. CureDuchenne Ventures’ early funding helps Duchenne science attract future investments made by venture capital firms, biotech and pharmaceutical companies.

Learn more at www.CureDuchenne.org. To help save the lives of those with Duchenne, please donate.
More than 400 people gathered at the Ritz-Carlton on Saturday, March 4 to enjoy the nectar of top Napa Valley wineries and help find a cure for Duchenne muscular dystrophy. The third annual Napa in Newport wine auction, powered by Karma, raised $1 million to support CureDuchenne’s mission to extend and improve the lives of those affected by Duchenne, a fatal genetic disease that causes muscle degeneration in children, typically boys. Those with Duchenne often lose their ability to walk by their mid-teens and the disease claims their lives by their mid-20s. Over the years, CureDuchenne has become the force behind considerable advances in Duchenne treatment, made possible by the help of gracious supporters. At this time, there is no cure for Duchenne.

The deLeuze Family of ZD Wines served as honorary chair for this year's sold-out Napa in Newport event. Founded in 1969, ZD Wines is committed to

Napa in Newport featured a meal created exclusively for the occasion by Chef Amar Santana of the celebrated Broadway by Amar Santana and Vaca restaurants. The dinner included a trio of baby Heirloom beets; crisp pear, candied walnuts, goat cheese, cocoa nib vinaigrette; blue cheese crusted filet mignon; smoked carrots, bordelaise sauce, curry granola; bourbon vanilla bean panna cotta; and Tarragon gel, compressed strawberries and chocolate pearls. Chef Amar has traveled the world collecting inspiration and accolades, including a position in the final round of Bravo’s Top Chef. A private dinner with Chef Amar Santana with wine pairings at Broadway by Amar Santana was auctioned off at the event.

The live auction also featured luxury travel experiences, rarely available wines and custom, once-in-a-lifetime Napa Valley experiences. Wine auction items included a vintner premier collection of more than 30 large format bottles of wine; St. Supéry and Davis Estates weekend that included a Formula 3 Racing experience; a day at the vineyard with famed winemaker Luc Morlet at Morlet Family Vineyards; a tasting at Veuve Clicquot and stay in a castle in Champagne, France; and VIP passes to the ZD Abacus winter wine escape.

As great wine and good company surrounded guests throughout the night, they were reminded of the true reason behind the event when Hawken Miller, a 20-year-old affected by Duchenne, took the stage. Hawken shared with the audience his experience battling Duchenne and how the disease has progressively made life more difficult.

“Just 10 years ago, I could play handball with my friends. Now I’m afraid that if I walk to far I might fall,” said Hawken. “Simple things, like getting out of a chair, making my bed, getting dressed, and writing have gotten harder and harder. I fall more frequently, and that’s one of the hardest parts of the disease. It makes me feel helpless. Being 20 years old with Duchenne is scary. I’m not supposed to have lived this long. The worst part is I don’t know how long I have left.”

The event also featured an impactful video that featured another young man with Duchenne, Jack Wolf, who joined Hawken on stage.

Read more.

Below are links to the Napa in Newport photo albums:

**Wine Tasting**

**Step & Repeat**

**Dinner**
Save the date for the Champions to CureDuchenne gala on April 8 at the University of Texas Golf Club. Join us for a magical evening to find a cure for Duchenne muscular dystrophy. The event includes cocktails, dinner, casino, live and silent auction. For more information, go to www.ChampionsForACure.org
CureDuchenne Cares Workshop For Families, April 8, San Diego, CA

Please join CureDuchenne Cares for a free, informative class on Duchenne muscular dystrophy on April 8 in San Diego, CA for family members and caregivers at UC San Diego Medical Education and Telemedicine Building from 8:30 am to 2:00 pm. Click here to register. For more information, contact Kylee Groon at Kylee@CureDuchenne.org or 949-872-2552.
CureDuchenne Cares Workshop For Families, April 22, Milwaukee, WI

Please join CureDuchenne Cares for a free, informative class on Duchenne muscular dystrophy on April 22 in Milwaukee, WI for family members and caregivers at the Sheraton Milwaukee Brookfield Hotel from 8:30 am to 2:00 pm. Click here to register. For more information, contact Kylee Groon at Kylee@CureDuchenne.org or 949-872-2552.