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**Scientist of the Month**

Douglas MacDonald, PhD

**Upcoming Events**

2nd Annual Knoxville

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Halo Therapeutics, LLC, a clinical-stage biopharmaceutical company developing novel therapeutics for rare fibrotic diseases, announced that it has received financial support totaling \$1.1 million from 12 not-for-profit foundations serving the muscular dystrophy patient community, including CureDuchenne.

Halo will use the funds to expedite the phase 2 study of HT-100, its lead drug candidate for Duchenne muscular dystrophy (DMD). HT-100, a proprietary formulation of halofuginone, is an orally available small molecule drug candidate being developed to reduce fibrosis and promote healthy muscle fiber regeneration in DMD patients. Halo will begin its phase 2 study in the second half of 2012.

"CureDuchenne is proud to be part of the Duchenne community that is financially supporting Halo," said Debra Miller, CEO and founder of CureDuchenne. "It shows the power of the Duchenne community to help fast track therapeutics, such as treatment of fibrosis, to help our boys. We thank Charley's Fund for initiating this research project."

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

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Summit, a UK drug discovery company, announced that it has dosed the first cohort of patients in a Phase 1 study of SMT C1100 for the treatment of Duchenne Muscular Dystrophy (DMD), a fatal, rare genetic disease characterized by rapidly worsening muscle weakness. SMT C1100, an oral small molecule compound, is a potential disease-modifying drug that works to increase, or upregulate, the amount of a naturally occurring protein called utrophin.

"There is currently no known cure for DMD, and the only treatments available mask the symptoms of the disease," said Glyn Edwards, Chief Executive Officer of Summit. "SMT C1100 has the potential to modify the underlying disease, and the initiation of this Phase 1 trial represents a great step forward in bringing our breakthrough science to patients suffering from DMD. We expect to report top-line data from the full trial before the end of this year."

SMT C1100 has been extensively evaluated in non-clinical efficacy and safety studies and has demonstrated its ability to restore and maintain the function of muscles. This Phase 1 dose-escalating clinical trial in healthy volunteers will evaluate if the Company's aqueous formulation of SMT C1100 can provide the consistent levels of drug in blood that non-clinical efficacy studies predicted would be required to confer therapeutic benefit in DMD patients, while also assessing its safety and tolerability. A successful outcome from this trial is expected to lead to a Phase 2 trial of SMT C1100 in DMD patients.

The Phase 1 trial is being supported by \$1.5 million from a group of US-based DMD organizations: the Muscular Dystrophy Association, Charley's Fund, Cure Duchenne, the Foundation to Eradicate Duchenne, Nash Avery Foundation and Parent Project Muscular Dystrophy.

SMT C1100 is designed to upregulate and maintain the production of utrophin. Utrophin is a protein that is highly expressed in regenerating muscle, but decreases as the muscle fibre matures and is eventually replaced by dystrophin, a protein that maintains the integrity and healthy function of muscles. Patients with DMD are unable to make dystrophin, resulting in muscle fibre degeneration. However, if utrophin is continually expressed in the mature muscle fibre, it can replace the function of dystrophin and thereby overcome the deficit in patients with DMD. This approach is expected to be a universal treatment for all DMD patients regardless of whether the disease was caused by an inherited or spontaneous genetic mutation. Summit has demonstrated in non-clinical efficacy studies that SMT C1100 is capable of increasing utrophin to restore and maintain the healthy function of muscles.

[Click here](#) to read more.

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## Sphingosine-1-Phosphate Enhances Satellite Cell Activation in Dystrophic Muscles through a S1PR2/STAT3 Signaling Pathway

A recent publication from Dr. Julie Saba et al., (Children's Hospital Oakland Research Institute, Oakland, California), highlights the role played by the signaling lipid sphingosine-1-phosphate (S1P) in controlling the fate of satellite cells (muscle stem cells) in mdx mice. The study demonstrates for the first time that mdx mice exist in an S1P deficient state by virtue of elevated levels of the catabolic enzyme sphingosine-1-phosphate lyase (S1PL). Therapeutic intervention with a small molecule S1PL inhibitor increased S1P levels and improved muscle regeneration in mdx mice after injury.

Further studies are needed to understand the significance of S1PL and S1P signaling in human muscle regeneration, but these preliminary findings suggest a feasible therapeutic strategy for enhancing satellite cell function.

For more information, [click here](#).

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## New CureDuchenne Website and Blog

CureDuchenne has launched a new website and blog. The new website includes the latest Duchenne research information, Duchenne care, upcoming events and how to take action to find a cure for Duchenne. The research section will be populated with the latest research news and information from CureDuchenne Chief Scientific Officer Dr. Michael Kelly.

The CureDuchenne website is user-friendly and provides a valuable resource for the Duchenne community and others interested in Duchenne. It includes photos, videos and links to social media. Check us out at [www.cureduchenne.org](http://www.cureduchenne.org).

The "A note from Debra" blog will include thoughts and insights from CureDuchenne Founder Debra Miller.

Keep checking back for updated research information and other features.

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**From Coast to Coast to Mt. Kilimanjaro, People Across the Country Will Climb to CureDuchenne**



CALM Dads

Thirteen teams from around the country will participate in the 4th Annual Climb to CureDuchenne: Pick Your Peak. Duchenne parents, friends and advocates across the country will pick a mountain, hill or tall building to climb to raise awareness and funds to find a cure for Duchenne muscular dystrophy, a lethal muscle disease that impacts 300,000 boys worldwide. The funds raised for Climb to CureDuchenne support the most promising research projects aimed at treating and curing Duchenne.



Luis Merino Luis Left Hook



Cook Family - Team No Boundaries

From 8-year-old Tyler Armstrong of Yorba Linda, Calif., who will be the second youngest person to summit Mt. Kilimanjaro in Africa, to regional climbs from California to Pennsylvania and Tennessee to Texas, people are climbing to raise awareness and funds to find a cure for Duchenne in June. In the past, Climb to CureDuchenne's elite team has climbed Mt. Rainer, Mt. Shasta and the Grand Tetons.

**This year's teams include:**

- Andrew & Brian's Buddies (San Diego)
- CALM Dads (Great Smoky Mountains Tennessee)
- Crystal Cove CureDuchenne Hikers (Crystal Cover Newport Beach)
- Hawken's Heroes (Mt. Kilimanjaro)
- Luis' Left Hook (Pasadena)
- Peace Valley (Peace Valley New Britain, Penn.)
- Sage Hill (Quail Hill Irvine, Calif.)
- Scooby Doo James (Visalia, Calif.)
- Team No Boundaries (Quail Hill Irvine, Calif.)
- Team Altura: Carter's Climbers (Mt. Rubidoux Riverside, Calif.)
- Team J&J (Texas)

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- Vaqueros (Quail Hill Irvine, Calif.)
- YP Team Climb to CureDuchenne (Quail Hill Irvine, Calif.)

To join or donate to any of these Climb to CureDuchenne teams [click here](#).



*Carter Blaze Team Altura: Carter's Climbers*

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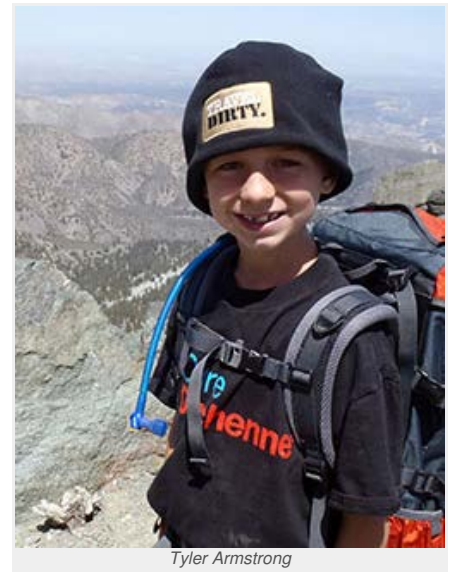
2nd Annual Knoxville

## Tyler Armstrong's Hike Generates Media Interest for CureDuchenne

In between training hikes, 8-year-old Tyler Armstrong is keeping busy doing media interviews to share his story on why he is climbing Mt. Kilimanjaro on behalf of the boys with Duchenne who can't climb. This increased awareness of Duchenne continues to help generate needed funds to help find a cure for Duchenne.

Tyler has recently been featured in:

- [The Orange County Register](#)
- [Yorba Linda Star](#)
- [Coast Magazine](#)
- [OC Metro](#)
- [PBS SoCal](#)
- [KABC](#)
- [KCAL9](#)



Tyler Armstrong

He also has additional local television interviews scheduled to air later in the month.

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**"Nobody Knows Their Time" Song to Benefit  
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British rocker Mark Emmins, former lead vocalist with UK rockers BLACKREIGN, has written and recorded the song "Nobody Knows Their Time" to benefit boys with Duchenne. Every download will make a difference for everybody living with Duchenne muscular dystrophy. Click here to download the song:

<http://dmdawareness.bandcamp.com/album/nobody-knows-their-time-e-p>

All proceeds from downloads will go to CureDuchenne to help fund critical Duchenne research. Be sure to share the link with family and friends.

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**Dealing for Duchenne Event Sparkles with Hollywood Vibe**



(from left to right) Debra and Paul Miller, Melissa Spencer, Stanley Nelson, M. Carrie Miceli, Amy & Chris Martin and Cathy Jones at the Dealing for Duchenne event on June 2.

More than 500 people attended the spectacular Dealing for Duchenne event on June 2 at the legendary Sony Pictures Studios in Culver City, Calif. The 5th annual event raised \$365,000 to benefit the Center for Duchenne Muscular Dystrophy at UCLA.

Guests enjoyed a fabulous buffet dinner by Wolfgang Puck, poker tournament, silent and live auction along with live music. Joel Murray, actor (God Bless America, The Artist, Mad Men, Shameless) was the auctioneer for the evening. Celebrities such as Oliver Hudson, Kelli Williams, Joe Francis, Kevin Weisman, Josh Malina, Kerry Norton and Jamie Bamber attended the event.

The inspirational program began with Duchenne parents coming on stage and holding up photos of their sons. This set the stage for Amy and Chris Martin's welcoming remarks thanking those in attendance for their support over the past five years.

"Due to your generous contributions and support from CureDuchenne, we are able to continually help fund the Center for Duchenne Muscular Dystrophy at UCLA, a place designed to push the limits of research, awareness, education and clinical care for our boys," said Amy Martin, co-chair of Dealing for Duchenne. "The presence of all those who attended reminds all of us that we are not alone on this journey and empowers us to push harder than ever to affect positive change."

Carrie Miceli, Ph.D., and Stan Nelson, M.D., co-directors for the Center for Duchenne Muscular Dystrophy (CDMD) at UCLA, spoke about the evolution of CDMD and how their son Dylan was diagnosed at a time when there weren't any Duchenne clinics in California and most families had to travel to the East Coast to receive treatment. [CDMD](#) is a world-class research center at UCLA providing coordinated clinical care as well as clinical trials to accelerate investigations into new treatments.

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George and Tyla Bohbot, the first major supporters of CDMD, were recognized at the event for their vision and financial contributions along with their son Josh, 22. Josh, who was diagnosed with Duchenne at age 6 and began using a wheelchair at age 10, is graduating from UCLA with a degree in design media arts. The Bohbot family received the 2012 Champion for Life award. Josh has been pivotal in providing input on the needs and challenges of living with Duchenne. His courage, strength and positive outlook on life has made him a role model for men with Duchenne and other disabilities on the UCLA campus and beyond.

Dealing for Duchenne was presented by Raines Feldman LLP. Other sponsors include Gibson Dunn, O'Melveny & Myers LLP, Trace 3, Ryan Partnership, CD Photocopy Service Inc., Wolfgang Puck Catering, Bacardi USA and Heineken. Thank you to our corporate sponsors, table sponsors and everyone who donated gifts to the silent and live auctions.

Thank you to the Dealing for Duchenne steering committee for its tireless efforts in pulling together a fabulous event. Thanks to the honorary committee of celebrities who have spoken for our cause and have helped raise awareness about Duchenne.

CureDuchenne also thanks Amy and Chris Martin and Cathy and Scott Jones for their outstanding efforts on behalf of CureDuchenne and for co-chairing this year's Dealing for Duchenne event.



*Duchenne families on stage during the Dealing for Duchenne program.*



*Josh Bohbot and his parents, George and Tyla, are honored during the Dealing for Duchenne event for their support of the Center for Duchenne Muscular Dystrophy. They are on stage with M. Carrie Miceli, Stanley Nelson and Melissa Spencer, directors of CDMD at UCLA.*

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CureDuchenne has been nominated for a CLASSY Award. The CLASSY Awards is the largest philanthropic awards ceremony in the country, celebrating the greatest charitable achievements by nonprofit organizations, socially conscious businesses and individuals worldwide. In 2011, nearly 2,000 organizations and volunteers were nominated for a CLASSY Award, and their collective efforts impacted the lives of more than 200,000,000 people in 71 countries worldwide.

To read the CureDuchenne achievement story, [click here](#). CureDuchenne is entered in the Health and Well Being Category in the West Region. StayClassy will determine the top five Finalists in each region in each category (16 categories total) based on impact, originality and category fit. The Regional Finalists will be announced to the public on July 9. For three weeks, from July 9- July 26 the public will have the opportunity to vote for their favorite candidate in each category.

Brewfest, June 23,  
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Climb to CureDuchenne,  
Pick Your Peak, June 23  
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Strike Out Duchenne  
Wooden Bat Tournament,  
July 12-July 15, Dayton,  
Ohio

Getzlaf Golf Shootout,  
September 8-9, 2012, Dana  
Point, Calif.

Champions to  
CureDuchenne, Newport  
Beach Gala, February 9,  
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Calif.

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### Family of the

## Cupcakes and Wine for a Cure



*CureDuchenne inspired cupcake.*

More than 50 people indulged in cupcakes and wine on Friday, June 8 in Tempe, Arizona, to benefit CureDuchenne. "Indulge" was an evening of sweet and savory cupcakes and wine pairings hosted by Duchenne parent Seavey Castelli. Guests mingled as they ate Carrot Cream Cheese, Chipotle Chocolate, Breakfast Club (French toast, maple and bacon), Roasted Strawberry Balsamic and Pirate's Booty cupcakes while sipping fine wine. Pirate's Booty (consisting of a pretzel crust, white chocolate cake and a salted caramel frosting) and Cinzano Prosecco was the hit pairing at the event! Indulge, held at Heidi's Events and Catering, also included a silent auction and raised nearly \$5,000 for CureDuchenne to help fund promising research.

The cupcakes were sponsored by Our Lady of Cupcakes. They will sell a CureDuchenne inspired cupcake at their location to help build awareness about CureDuchenne's mission to raise funds to find a cure for Duchenne. This cupcake features a CureDuchenne logo made out of colored white chocolate and will include information about Duchenne in the box.



*Duchenne moms "indulge" at the cupcake and wine fundraiser.*

"We are glad the community came together for a fun and sophisticated evening while raising much needed funds to find a cure for Duchenne," said Castelli, Duchenne parent and Indulge event organizer. "This event helped heightened awareness of Duchenne in the Phoenix community."

Thank you Seavey for your time and effort to create this special event in your community! Every dollar raised is a step closer to finding a cure for Duchenne.

## Month

The Martin Family

## Scientist of the Month

Douglas MacDonald,  
PhD

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*Guests enjoy the Indulge event while raising funds to find a cure for Duchenne.*

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### Upcoming Events

## The Martin Family



*The Martin Family (left to right Derek, Will, Amy, Chris and Nathalie)*

Will Martin, 10, loves sports. He is a huge basketball fan and Sports Central fanatic. He can recite sports statistics and keep adult fans on their toes with his knowledge. Unfortunately, Will can't play the sports he enjoys watching. He was diagnosed with Duchenne at age 5.

When Will was diagnosed, parents Amy and Chris Martin's friends came together and asked how they could help. They wanted to plan an event and help fundraise. Amy and Chris have volunteered their entire lives helping out at school and coaching sports teams for their son Derek, 16, and daughter Nathalie, 12. Now their friends wanted to pay it forward to help Will and other boys with Duchenne. That is how the annual Dealing for Duchenne event in Los Angeles came about. That same group of friends have been part of the steering committee and planned the successful event the past five years. The event has grown each year (see Dealing for Duchenne article).

"We have always wanted the event to be celebratory," said Amy Martin. "Attendees look forward to Dealing for Duchenne because it starts out fun, we pull on the heartstrings and then end on a high note. People are inspired to donate and leave the event having an enjoyable evening while helping out our Duchenne boys and young men."

When Paul and Debra Miller, founders of CureDuchenne, first met Amy and Chris, it was easy to see why they have such a huge support group. They are sincere and loyal friends and when they were in need, their community gathered around just as they have always supported their friends and family. It's been a joy to get to know Amy and Chris and their family.

CureDuchenne thanks the Martin Family for their never ending support. Their dedication to raising money to find a cure for Duchenne in an upbeat and positive way is inspiring.



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## Scientist of the Month - Douglas Macdonald, PhD.



*Douglas MacDonald, PhD*

Dr. Macdonald joined CureDuchenne's Scientific Advisory Board in 2009 after Debra Miller was introduced to him by Amy Martin, a Duchenne parent. Soon after, he chaired the first and now annual CureDuchenne Scientific Summit. The purpose of the Summit is to bring together world leaders in Duchenne's research to review the many possible therapeutic approaches for DMD and to provide strategic advice to CureDuchenne on which projects look to be the most promising for support.

Dr. Macdonald is Director, Drug Discovery at CHDI Management, Inc., a privately-funded, not-for-profit biomedical research organization that is developing therapies that will slow the progression of Huntington's disease (HD), an inherited genetic neurodegenerative disorder. In HD, a mutated form

of the huntingtin gene is expressed resulting in a toxic protein. A promising therapeutic approach being developed by CHDI is to suppress the expression of this mutated protein using oligonucleotide compounds. This type of technology is also being used for DMD, but in the case of Duchenne, one can also use these types of compounds to increase the expression of dystrophin, the protein deficient in the muscles of boys with DMD. Dr. Macdonald's expertise in these approaches has allowed him to advise CureDuchenne on several such projects and to also work with DMD researchers on projects of their own.

"I am constantly amazed and inspired by the commitment of families to understand and work towards therapies for rare genetic disorders. Huntington's disease is similar to Duchenne in that regard and it is extremely motivating for researchers," said Macdonald.

Dr. Macdonald's experience working at several large pharmaceutical companies gives him a unique perspective in drug discovery and development for rare diseases.

"CureDuchenne provided early seed money for Prosensa and look how far they have come," said Macdonald. "None of that would have been possible without foundation support. Whether it is for DMD, Huntington's, or other rare diseases, foundations play a critical role in helping move the research forward."

Rare diseases are often very complex scientific problems, but it is the human factor that inspires Macdonald. "We work very hard in both the preclinical and clinical arenas to ultimately gain FDA approval so that we can improve people's lives with effective treatments for the patients and families we meet."

Macdonald received his Ph.D. in Pharmacology and Experimental Therapeutics at the Boston University School of Medicine and his Bachelor's degree in Chemistry from Trinity College (Hartford, CT). He is a member of the Society for Neuroscience, New York Academy of Sciences, and the American Society of Pharmacology and Experimental Therapeutics. He is currently a member of the NIH/NINDS Neuropharmacology and Diagnostics Small Business Innovation Research Study Section and a Lecturer at the University of Southern California

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## 2nd Annual Knoxville Brewfest, June 23, Knoxville, Tenn.

The 2nd Annual Knoxville Brewfest will be held on June 23 in downtown Knoxville, Tenn., at the historic Southern Railway Terminal from 4 p.m. to 8 p.m. This craft beer tasting festival will celebrate great beers, breweries and beer enthusiasts. All net proceeds will benefit CureDuchenne. Tickets are \$38 and include beer tastings. We encourage you to buy tickets online before the event because they expect to sell out.

[Click here](#) to register.

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## Climb to CureDuchenne, Pick Your Peak, June 23 and June 30, Nationwide

Teams of people from around the United States pick a mountain, hill or tall building to climb to raise funds and awareness for Duchenne. The fourth annual event features the Elite Team, led by 8-year-old Tyler Armstrong, of Yorba Linda, climbing 19,341 ft. to the summit of Mt. Kilimanjaro in Africa. Armstrong is one of the youngest to climb Mt. Kilimanjaro and is serving as the Honorary Spokesperson for the 2012 event.

**What:** Teams of people across the country climb a mountain, hill or tall building to raise funds and awareness for CureDuchenne. This is the fourth annual event and hundreds of people will participate. All funds donated will be used for research and to raise awareness for Duchenne.

**Where:** No geographic limitations. Anyone, regardless of athletic ability, is encouraged to participate individually or to form a team and secure personal sponsors/contributors for completing the climb.

**When:** June 23, 2012 or June 30, 2012. If those dates do not work for you, please select another day that is more convenient. (Elite team to climb Mount Kilimanjaro June 25 - July 2, 2012)

**Cost:** Registration fee is \$25, includes CureDuchenne t-shirts.

[Click here](#) to register

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## Strike Out Duchenne Wooden Bat Tournament, July 12-July 15, Dayton, Ohio

From July 12 through July 15, 2012 the Strike Out Duchenne Wooden Bat Tournament will host over 60 teams from around the region at the Brick City Sports Club fields in Dayton, Ohio over four days to raise funds and awareness for CureDuchenne.

Calling all Duchenne families in Ohio, Indiana and Kentucky! This exciting tournament will hold a special Duchenne Game on Saturday, July 14th so Duchenne boys have the opportunity to play the game (indoors) at their own level in a safe and supportive environment. The Brick City Blast players will guide and support Duchenne boys no matter their abilities or mobility so that they can enjoy being an athlete for the day!

Those who participate will receive a game T-shirt and, along with their families, will be treated to burgers, refreshments and an outdoor concert following the game. Don't miss this incredible opportunity!

#### Event details:

- **Date:** Saturday, July 14, 2012
- **Time:** 4:00 p.m.
- **Location:** Action Sports Center, 1103 Gateway Drive, Dayton, Ohio 45404

Space is limited and will be offered on a first-come, first-served basis. Those interested should contact Peggy Larson at 949-872-2552.



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**Getzlaf Golf Shootout, September 8-9, 2012, Dana Point, Calif.**

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 awards ceremony is at 4 p.m.

[Click here](#) to register.

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**Champions to CureDuchenne, Newport Beach Gala,  
February 9, 2013, Newport Beach, Calif.**

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

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