

FIND-A-CURE

Spring 2005

for Children with Duchenne, Inc.

**Funding Research for
Treatments or the Cure
for 100,000 Boys in the
US and Countless
More Worldwide**

Dr. Marks Heads Up Neuro-muscular Program at St. Christopher's Hospital in Philadelphia



*Dr. Harold Marks -
Head of the Neuro-muscular Program at
St. Christopher's Children's Hospital in
Philadelphia, PA.
and Scientific Liaison to Find-A-Cure*

Dr. Harold Marks, a long time clinician in the field of Duchenne Muscular Dystrophy, recently accepted a position as head of the Neuro-muscular program at St. Christopher's Children's Hospital in Philadelphia, PA. Dr. Marks was previously tenured at A. I. duPont Children's Hospital of Delaware, Nemours Children's Clinic in Florida...and Children's Hospital of Philadelphia (CHOP) prior to his recent move to St. Christopher's. While at A.I. duPont, Dr. Marks, in conjunction with Dr. Vicky Funnage, pioneered investigations of the use of prednisone and a compound called Hemin as potential treatments for Duchenne Muscular Dystrophy. Find-A-Cure supported and funded several studies at A. I. duPont, to this end. Hemin, in vitro (laboratory), has promising potential in reducing fibrotic tissue growth while accelerating muscle tissue growth. Duchenne Muscular Dystrophy occurs in one out of every 3500 male births with devastating effects. On the average, loss of ambulation usually occurs by the age of ten and most boys succumb in their teen years. To date, there is no know treatment or cure for the disease.

Last year, Dr. Marks agreed to act as the scientific liaison for Find-A-Cure. He also proposed a coordinated scientific research effort and a possible sponsored clinic through Find-A-Cure between area children's hospitals. We look forward to working again with Dr. Marks, Mrs. Nedra Marks (a medical illustrator), and St. Christopher's Children's Hospital as we press for a treatment or cure for Children with Duchenne.



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*Jill Burt, Sarah Punderson, Adrienne Ballingall,
Dan Janquitto and competitors at the
Toms River Country Club
Annual Tennis Round Robin 2004*

FIND-A-CURE's Philosophy:

Why does FIND-A-CURE's strategy work? The answer is due to several reasons:

1) The Nemours research facility is directly linked to the A.I. duPont Children's Hospital. Unlike other research facilities, Nemours does not operate in a vacuum separated from its patients. Results are moved quickly from research to the hospital.

2) The Board of Directors of Nemours have instructed that any studies must ultimately end in clinical applications for children as quickly as possible.

3) FIND-A-CURE has studied how general research in the U.S. is undertaken. Under the more common general grant process, it may take several years before rounds of research are completed. The board members of ***FIND-A-CURE*** initiated the cooperative agreement process used by NASA to reach the moon. Under this system, the funding agency sets the direction of the research with specific goals and time lines.

4) ***FIND-A-CURE's*** bylaws dictate that no less than 80% of donations be dedicated to research, while strongly pushing to exceed this minimum mark. All funds are dedicated to research.

FIND-A-CURE does not provide funding for support services. We fund directed, goal-oriented, targeted research that will lead to clinical help for these children.

5) ***FIND-A-CURE*** is an all volunteer organization. We have no paid or compensated directors or employees.

Perpetual Tennis Trophy Winners for 2004



It is time to once again thank Jill Burt, Sarah Punderson, and Adrienne Ballingall for arranging and conducting the Toms River Country Club's Ocean Tennis Center Find-A-Cure Annual Round Robin. Last year a perpetual trophy was established for this annual classic event. As always, the weather was absolutely gorgeous. Jill and Sarah served lunch to everyone, after which Dan Janquitto spoke to the group about Children's Duchenne. Thank you... Jill, Sarah & Adrienne!

ROBIN WINNERS 2004:

Jill Burt & Vera Breunig



***Tell your friends who are employed
by state or local governments
to specify Find-A-Cure
No. 2507 for donations during the
CFC this fall!***

***Combined Federal Giving
Campaign No. 2507***



DID YOU KNOW?

***Find-A-Cure accepts MasterCard, Visa,
American Express and Discover to make
your gift giving more convenient.***



"Moonchaser" & the Aruanno's

John & June Aruanno have been conducting evening cruise fundraisers on board the "Moonchaser" for the last several years on behalf of their son and all of the children afflicted with Duchenne. In addition, they have also hosted Pampered Chef events. If you are in the New York area, call us so we can give you details about their efforts & events. Thank you more than ever, John & June!

To our extended family at Toms River Kiwanis AM...

Thank you again for your sponsorship and support. As always, your friendship and interest is heartfelt and gratefully appreciated. In addition, Kiwanis AM once again presented an additional donation at the dinner after a day of golfing. As always, it was great to see President Ed Okuniewicz & our Kiwanis friends and supporters! We are indebted to you for your generous emotional and financial support.

Find-A-Cure educates the public at SAILFEST!

Find-A-Cure went all out this year at the annual Toms River Sailfest held on the streets of Island Heights, NJ. Displayed were a 1944 GMC CCKW Cargo Truck, a 1942 Willys MB Jeep, a 1943 Ford GPW Extended Body Coast Guard Jeep, and a rare 1943 German Tracked Motorcycle called a Kettenkrad. These vehicles were certainly attention getters and went a long way in helping to educate literally thousands of Sailfest participants regarding Children's Duchenne.

GOLD SPONSORS abound at Colts Neck Annual Golf Classic

This year's Golf Classic at the Colt's Neck Golf Club broke all existing expectations and records for a Find-A-Cure fund-raising event. While raising over \$43,000, more fun was had by all! This year, we had an extraordinary number of gold sponsors which contributed to our record earnings including Greater New York Mutual Insurance. We must make special mention of our new friends, Warren Heck (Chairman) and Angelo Tartero (Marketing Manager). We enjoyed meeting them and other Greater New York Mutual employees and appreciate their support. Games of the day included a \$50,000 shoot out, a putting contest, longest drive, free car with a hole in one, and more. Down's Ford and Circle Auto Group once again supplied the 2004 Hole-in-One automobiles. Prizes and donations from supporters and local merchants reached an all time high, which contributed to the record donations! We do not know how to thank you enough! Katie Frankovich, Andy DeFeo, Pat Bailey & friends, Cheryl Murphey, Muriel Rosenfeld, Nels Warren, Lori Farnkoph, Nick & Nancy Janquitto, and others, helped with all of the support functions of the day. Nick Palumbo was the center of attention as the MC for dinner. Crown Beer again supplied the libations for our thirsty players! This year's event was again graciously catered by Carrabba's Italian Grill of Brick, New Jersey. Chris Blythe and his crew from the Brick



New Sponsors & Friends from Greater New York Mutual

Carrabba's, coordinated with other Carrabba's partners and restaurants from all over the northeastern United States. To make this event a success, these restaurants prepared and served all of the food on their free time at no cost to Find-A-Cure! To top it all off, Chris' brother, Todd, showed up with the Carrabba's Racing Team to round out the day. Additional support in the form of donations came from Pam Onori's Dreams & Beyond, Inc. and from the United Methodist Women of Island Heights. It was the BEST event yet, and by all indications it will keep on getting better.

Amanda...and one easy lesson on HOW TO SELL GOLF BALLS!

If you have ever had the privilege to stand on a corner shaking a can, or giving your spare time soliciting for a good cause...you already know that it is both rewarding and not for the faint of heart. We tried something new this year at the Carrabba's restaurants in the immediate area. Stephen Hallett coordinated an all out battle of wits between competing restaurants in an effort to sell \$1.00 paper golf balls for Find-A-Cure's cause. Each and every Carrabba's employees went above and beyond the call of duty and raised over \$13,000 in 30 days of sales. Of all of the stores, and all of the employees, Amanda Pierce of the Chadd's Ford location topped everyone with \$2500. How'd she do it? We are not quite sure, but we believe that she took Carrabba's philosophies to the max in order to make each and every sale. Besides making herself very familiar with Find-A-Cure methodologies, she just plain out smiled and sold the heck out of the golf balls. Thanks Amanda and each and every Carrabba's employee.



Dave Sizelove & Aquatherm Industries...

It was great to see our long time friend, Dave Sizelove, and others from Aquatherm Industries. This year Dave won the 50/50 raffle at dinner and so graciously donated his share back to the Duchenne children. Thank you Dave, Chuck, and supporters from Aquatherm. You are great friends!

Find-a-Cure for Children with Duchenne, Inc.

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**How many times are you offered an opportunity to make a difference...
really make a difference... in the life of a child?**

Web Site: www.findacure.com E-mail : findacure@comcast.net



*Veteran's Day Parade 2004 - Toms River, New Jersey
A Lakewood, NJ contingent of "Soldiers" dressed in authentic uniforms dating
back to the Revolutionary War*

Parades



Find-A-Cure continues to support patriotic parades in 2004. This has proven to be a wonderful venue that not only supports our country and honors veterans, but also very visibly gets the Find-A-Cure message out to the public. This years events included Memorial Day, 4th of July and Veteran's Day. In addition, educational programs were initiated at Southern Regional High School in Stafford NJ in the fall and spring with resounding acclaim. During this last year, Find-A-Cure volunteers, traveled to several states at their own expense in order to recruit other antique military vehicle owners in the war effort to end Children's Duchenne!

Segway...and Golf?

Segways are head turners unto themselves. Put Anthony atop one from Shore Mobilities with his golf bag and now you have a sight! This Segway was demonstrated as a potential "personal golf cart" at this years Colts Neck Golf Classic for Find-A-Cure. Want to see more? Peek inside!



"Science that makes a differencefor children"