



the hope and light foundation
benefiting children with sma

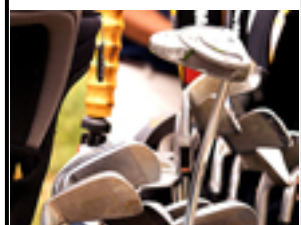
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Hope and Light: A Bright Future

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The Hope and Light Foundation was founded in December of 2004 by Aaron and Stephanie Miller.

Stunned by the diagnosis of their first child with SMA Type I, the Millers dedicated themselves to caring for their daughter and finding a cure for a disease they had never heard of. The Millers quickly learned that their daughter, stricken at only three months of age, had an expected life span of merely six months. They also learned that SMA was virtually an unknown disease that affected thousands of children every year.

Despite large support groups and vocal parents fighting for their children, SMA has been overlooked in research funds and awareness, in favor of more publicly noticeable diseases. Even though SMA is as common as other genetic diseases like ALS, Cystic Fibrosis and Sickle Cell Anemia, it is behind in research funds, left off legislation that provides assistance to fami-

lies, and most doctors in this country consider SMA children untreatable. Despite SMA's unknown status and lack of research, Hope and Light and other organizations, including the National Institute of Health, believe this disease is curable.

The first glimmer of hope, on what has been a very dark horizon for SMA sufferers, came in 1995. Researchers pinpointed a gene on chromosome 5 that was missing or defective in 95% of all SMA cases. This gene is known as the Survival Motor Neuron (SMN) and it is crucial in creating the proteins necessary for motor neuron survival. More hope followed when SMA was selected by the NIH as the prototype for their accelerated drug discovery effort – singled out as the condition closest to treatment out of more than 600 neurological diseases. Researchers estimate that a treatment, and possibly even a cure, for SMA can be reached with a research

investment of twenty to thirty million dollars per year for the next five to seven years. **With the proper funding**, researchers can focus their efforts

“a research investment of twenty to thirty million dollars per year for the next five to seven years” -estimate for a cure/treatment given by SMA researchers

toward increasing SMN protein levels through new drugs and gene therapies.

The Hope and Light Foundation plans to help close the funding gap and educate the public about this devastating disease. The Miller's are grateful to have celebrated their daughter's third birthday on February ninth and look forward to the day when a cure for all SMA families can be found.

Letter From the President:

It has been just over 2 years since the launch of The Hope and Light Foundation. Since its inception, the foundation has been dedicated to stopping Spinal Muscular Atrophy and its attacks on our families and children. We are looking forward to the hope we can offer the SMA community in 2007.

2006 was a big year for the foundation. As our family moved from California so did the Hope and Light headquarters. We now enjoy working out of Atlanta, Georgia. In the spring, the South Carolina chapter organized the first Hope and Light Charity Golf Tournament. The money raised from the tournament enabled us to fund our first research project. We are six months into supporting a drug trial at Stanford University Medical Center under the

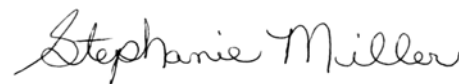
direction of Dr. Ching Wang.

For 2007 we have big plans in mind. First on the agenda are substantial improvements to our website, www.HopeandLight.org. Volunteers will work to bring newsletters and updates to you throughout the year. We are also excited about new brochures in the works which will help raise the general awareness of SMA throughout our communities.

Through donations, support, and encouragement, our donors have played a valuable part in the successful start up of Hope and Light. I would like to say thank-you for sharing our commitment to the SMA cause; you are helping make Hope and Light a resource that will save and improve the lives of children

suffering from this devastating disease. It is only through your generous support and partnership that we are able to fulfill our mission and save lives. By donating and learning about SMA you are joining us in the fight to end this common, yet “unknown” disease, and I am deeply grateful and proud of your efforts.

Sincerely,



Stephanie Miller

“The money raised from the tournament enabled us to fund our first research project.”

The Mission of Hope and Light:

The Hope and Light Foundation is dedicated to the following goals.

1. Finding a cure for SMA through research
2. Changing SMA from an “unknown” disease to putting it on the forefront of the medical community
3. Be a resource to families by educating and forming communities around surviving SMA until a cure can be found
4. Assist the medical community in communication and distribution of knowledge about recent advances in SMA

2006 Fundraising Report:

The Hope and Light Charity Golf Tournament held on May 26, 2006 was a huge success! Golfers hit the course at Carolina Country Club in Spartanburg, South Carolina. Twenty-eight teams enjoyed a beautiful day on the links and then it was off to Holly Hall for hors d'oeuvres and a live auction. A silent auction was also in full swing throughout the day. The total tournament income was \$102,785!

“I am so proud of everyone who worked to make the event a success, but even more proud of the money we raised to help find a treatment or cure for SMA,” said Tournament Chair, Amanda Lawson.

The committee of twelve worked quickly to put the tournament together in less than six months. The fundraiser attracted close to sixty businesses and individuals as event sponsors. Stock Building Supply supported the tournament as presenting sponsor.

“The South Carolina Chapter did an incredible job of organizing the tournament”, said Hope and Light President Stephanie Miller. “We appreciate everyone who participated locally and from afar.”

The Hope and Light foundation is thankful to the sponsors, volunteers, donors and 112 golfers who helped make the golf tournament possible. Congratulations to the winning foursome of Ben Carter, Evin Martin, Rodney Tapp and Robbie Beirshank. Everyone who attended left knowing they were helping families win the battle against Spinal Muscular Atrophy.



Golf Tournament Sponsors:

Presenting

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AMCOR
Clayton Tile Distributing Company
Extended Stay Hotels
Galloway Promotions
Hughes Supply
Robbins Brick & Block

Silver

Advanced Door Systems
Allen Funk's Wallpaper
Coldwell Banker Caine
Dave Edwards Toyota/Hyundai
Fieldin Culbreth & Family
J. Bulman Company
Joe & June Griffin
Mark III Properties
Master's Mark Dry Cleaners

Bronze

Builders Firstsource
Cannon Supply
Chick-fil-A
Classic Marble, LTD
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Jones Electronics and Appliance Repair
Lance, Inc.
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R&R Enterprises
Spenser/Hines Properties
Steve Noblin
Stone Lighting
Tri-Ad Machine
Upward Unlimited
Vic Bailey Ford
WP Law, Inc.



Support Hope and Light

YES! I WANT TO SUPPORT SMA RESEARCH!

Please be sure to include this completed form with your donation. All checks should be made payable to:

The Hope and Light Foundation
1355 Cortez Lane NE, Atlanta, GA 30319

Name

Address

Email/Phone

- I have included \$ _____ to support the fight against SMA
- I would like to pledge \$ _____ per month and have included my first pledge payment
- Please keep my donation anonymous
- Please keep me updated on events and research news



How to Get Involved

The Hope and Light foundation is an all volunteer, organization. We are looking for people to support us financially in our quest to cure this disease. We are also looking for talent in several areas of our organization; this could involve answering phones, working information booths, and gathering support from friends and family. If you would like to be a volunteer contact us at the email address below.



1355 Cortez Lane, NE, Atlanta, GA 30319
www.HopeandLight.org info@HopeandLight.org