



## HOPE AND LIGHT MOVES STANFORD DRUG TRIAL FORWARD

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The Hope and Light Foundation is proud to announce its first research grant to Dr. Ching H. Wang of Stanford University Medical Center. Supporting Dr. Wang's research is a significant step to achieving the Foundation's primary mission to bring about a cure for Spinal Muscular Atrophy.

Dr. Wang is the director of the Pediatric Neuromuscular Clinic



*Dr. Ching Wang sees SMA patients at Stanford University Medical Center. He also spends countless hours in the SMA lab at Stanford.*

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### LETTER FROM PRESIDENT:

Dear Friends,

I hope this newsletter gives you an inside view of how we operate and what motivates us to continue fighting this unrelenting disease called Spinal Muscular Atrophy. In this issue, we have included an informative interview with our first grant recipient, Dr. Ching Wang. Unwavering support from our donors allowed the foundation to reach a major goal of awarding this grant within one year of gaining 501(c)(3) status. I believe this milestone reflects the depth of compassion our investors feel towards children suffering from SMA.

I am proud of what we have accomplished together and excited about the future. Philanthropy will remain critical as the foundation grows. We are doing more than raising money for a good cause; we are striving to save the lives of thousands of children around the world. However, we will need widespread support to reach this ambitious goal. On behalf of the families and children battling SMA, I thank you for being part of our community of supporters.

Warmest Regards,

Stephanie Miller, *President*  
The Hope and Light Foundation



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and an associate professor of neurology and pediatrics at Stanford's School of Medicine. As a leading researcher on SMA, he is the first to conduct an FDA approved clinical trial using a drug called hydroxyurea in children with SMA. In an interview with HLF staff writer, Dr. Kevin Miller, Dr. Wang answers questions about the Foundation's involvement with his groundbreaking research.

### *1. How has the Hope and Light Foundation grant impacted your research progress?*

Dr. Ching H. Wang (Dr. Wang): The Hope and Light Foundation grant enabled the continuation of our clinical trials without disruption and supported our basic research in the lab to study the molecular mechanism of SMA motor neurons death. The SMA clinical trial projects that we started in 2004 have turned out to take much longer and require much more financial support than what we had originally estimated. We were (and still are) at risk of terminating these studies prematurely if not for the support from the Hope and Light Foundation.

### *2. How many children are currently enrolled in the study?*

Dr. Wang: We have completed enrolling 24 patients in the types II/III project. Eight of them are still in the trial. We have also completed enrolling 18 patients in the type I group. Twelve of them are currently still in the trial.

*"This is a time that your investment in this area will be worth a great return when you look back 10-20 years from now. I am sure you can proudly say then that your contribution facilitated that critical discovery."*

*- Dr. Ching Wang*

### *3. How many more subjects are needed for your study?*

Dr. Wang: We are currently not able to proceed with one of our recently enrolled type I child because he is on the ventilator now. We probably will need to replace him with a new patient. After we complete our 18th patient in the type I group we will need 18 months to complete the study.

### *4. Ideally, how much additional funding is needed for the study to be completed as planned?*

Dr. Wang: Judging by the past few years' expenses, if we are able to complete our studies in 18 months then we will need another year and a half of funding. We have been spending about \$150,000 per year for the clinical trial projects. So, we will probably need about \$200-250,000 in order to complete the projects.

### *5. Is there any other information you would like to convey to Hope and Light volunteers and contributors?*

Dr. Wang: Hope and Light volunteers and contributors are providing your support in the most timely manner. The SMA research is in the juncture of critical discovery and your help will certainly facilitate that discovery. This is a time that your investment in this area will be worth a great return when you look back 10-20 years from now. I am sure you can proudly say then that your contribution facilitated that critical discovery.

## Seven Core Values of the Hope and Light Foundation

Our faith in God drives us; it gives us certainty in a future without SMA.

We believe medical science has the ability to eliminate the pain and suffering of genetic disease, making the future of an afflicted child better than their past.

By our work, we respect and honor the struggles and hardships of families fighting for the lives of their children.

We believe in the community's ability to solve social problems that our government and commercial medicine are unwilling or unable to take on.

We value the dignity of life, as it exists in a child.

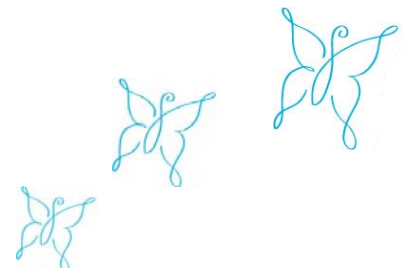
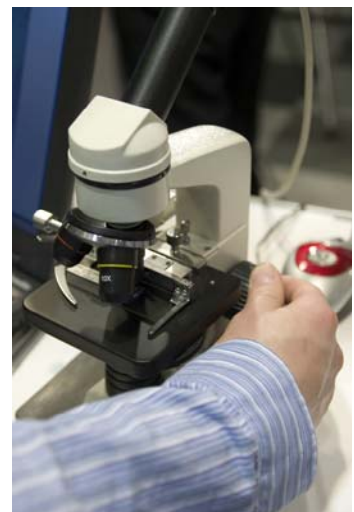
We believe we can remove the fear of the unknown in childbirth, caused by genetic disease.

We believe curing SMA is a foundational step in eliminating childhood genetic disease.

### **Georgia Governor Signs Proclamation in Honor of SMA**

August is National SMA Awareness month. In 2006, The Hope and Light Foundation was instrumental in gaining statewide recognition of SMA in Georgia. Governor Sonny Perdue signed a proclamation declaring August SMA Awareness Month. Governor Perdue has once signed a proclamation for 2007. We thank him for his support!

To help us spread the word about SMA this month and all year long, please tell your friends and family to log onto our website at [www.HopeandLight.org](http://www.HopeandLight.org).



[www.hopeandlight.org](http://www.hopeandlight.org)

Our website has been updated and now giving to the HLF is easier than ever before. When you visit our website, look for the donation button and make your secure online gift.

An automated donation each month provides the Hope and Light Foundation with a steady source of support, reduces processing and mailing costs, and spreads your contribution out over the year. To make a credit card donation, please visit us at [www.HopeandLight.org](http://www.HopeandLight.org).

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

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Name

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Address

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- 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



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