

FightSMA

SPINAL MUSCULAR ATROPHY

May 2008

Tax ID 501(c)(3) 38-3537413

Volume 9, Issue 1



Let Your Voices Be Heard



This year was my sixth trip to Washington, D.C. and each visit is more energizing than the last. To see our democracy in action is a great and wonderful experience that I will never tire of. Once again I was joined by over 30 other families from across the U.S.A. that have been effected by Spinal Muscular Atrophy. This year our goal was to socialize the benefits of our progress of the last year and seek support for the SMA Treatment Acceleration Act Bill (HR.3334 and S.2042). We presented the bill to all of our elected officials in the hopes they would be willing to support this critical legislation. Please see

the area below on how you can help get these bills passed and make it possible for our researchers to obtain additional funding. SMA researchers have blessed us by finding several drugs that have shown promise in the research settings. Many of these compounds are ready to move in clinical trials. This takes money—A LOT OF MONEY! The proposed SMA Treatment Acceleration Act would provide an additional \$30 Million in funding to the National Institute of Health to conduct clinical research trials that will ensure the safety and effectiveness of these drugs. This research will benefit not only SMA patients, but also serve as a springboard for research for other diseases. In his 2008 research update to the FightSMA board of directors Dr. Alex MacKenzie, (M.D., Ph.D., University of Ottawa) stated that “SMA genetic research is providing a novel model for effective treatments not just for this one condition, but for a much wider array of disorders. This gene modulation is proving to be usefully employed in the hunt for drugs for diseases such as Tay-Sachs Sandhoff, Parkinson’s, Alzheimer’s, Deafness/Dystonia, Friedreich’s Ataxia, and others...” We are very encouraged with the progress on every level...but there is still a great deal of work that needs to be done, financial support is needed now more than ever!

Thank you for your continued support!

Joe and Kris Cueter

Looking Back At Our Progress

- Prior to 2003 the US Government had only budgeted \$5 Million annually on SMA research.
- 2005, the National Institute of Health recognized SMA as a leader of research for all 600 orphan diseases and provided a small increase in funding.
- 2006, our second big conquest...the SMA project. Funding is currently \$15 Million per year for SMA research.
- 2007, SMA Organizations unite to form one voice in DC and bring one message to the Hill. Increase funding for SMA!
- The SMA treatment Act, when passed in 2008, will provide additional money to be used on national clinical trials in an effort to demonstrate that new treatments are safe and effective in SMA patients. This bill would bring SMA funding to \$45 Million per year!!! A \$30 Million Dollar boost from today.

PLEASE HELP, DO THIS NOW!

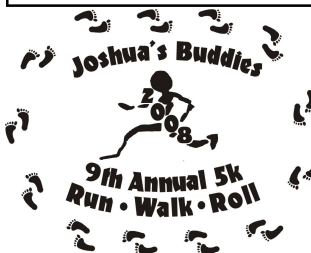
Contact your Senators and House Representative

<http://www.congress.org/congressorg/home/>

Now it is up to us to motivate our elected officials throughout these United States to sign on in support of this important legislation. Please do this in the next few weeks to capitalize on the momentum that our SMA families have just created with our recent trip to the Hill in late April.

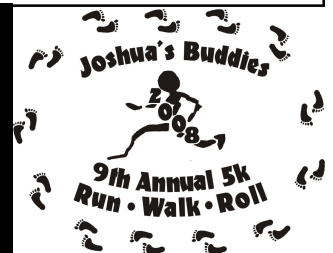
- Go to the web address above, find all of your elected officials and send them a note via e-mail asking them to support either the Senate or the House version of this bill (HR.3334 or S.2042) because this is what matters...children's lives.
- Ask your member to support this legislation in order for these bills to pass later this summer.

Do not delay, there will be more one and two year old children who will die while you wait—you and I must be their voice to get this legislation passed. Our efforts can help end the pain for these children, their families, and the children yet to come!



9TH ANNUAL 5K FOR SMA
JUNE 21, 2008 TROY, MICHIGAN

go to www.fightSMA.org/index.php?fam_joshua
to download registration information



SMA is the most common genetically determined cause of infant death.

FACTS ABOUT SMA

7.5 Million Americans are recessive carriers of SMA and they do not know it...One of them could be you!

- * Spinal Muscular Atrophy (SMA) is the number one inherited cause of death in children under the age of two.
- * SMA is an often fatal disease that destroys the nerves controlling voluntary movement, which affects crawling, walking, head and neck control and even swallowing.
- * One in 40 persons are carriers of the SMA gene.
- * One in 6,000 babies born is afflicted with SMA.
- * 50% of those diagnosed before the age of two will die before their second birthday.
- * SMA can strike anyone of any age and of any ethnicity.
- * SMA is the #1 inherited cause of death in children under the age of two.

Thanks to our 2007 5K Sponsors

Arbor Vacuum & Appliances	Auto Cycle Marine
Autos Etc. of Michigan	City of Troy
Commerce Psychiatric Services	Cueter Brothers Service
Cueter Candy	Cueter Chrysler Dodge
Detroit Flexible Metal	Industrial Distribution Group
JCW Computers & Entertainment	J. Danhausen Custom Builders
J.M. Sales and Associates	John Cueter Family
Kenneth J. Bonk, DDS Paul A Renke, DDS	Law Office of John Simon
Mari Lynn's "S" Cookies	Martell Elementary
McK's Wine Shoppe	Rosco The Clown
Tytin Printing	U.S. Manufacturing
Walled Lake Northern HS	Whole Foods Market

FightSMA Michigan

PO Box 764 Troy, MI 48099-0764
cueters@wowway.com

Joe and Kris Cueter

248-828-2870

www.fightSMA.org

All donations to **Joshua's Buddies**
are Tax Deductible.

The 2008 5K for SMA is HERE...

Help us by getting your sponsorship in by June 1st, 2008.

Company's Name _____

Your Name _____

Address _____

City _____ Zip _____

Phone Number _____

E-mail _____

Donation amount _____

\$250
and Your
Company
Logo will go
on our Run
T-Shirt

Return this form with your donation and a copy of your logo.

You can also send us your logo by e-mail as a JPG or BMP file to MI@FightSMA.com. If you have been on a t-shirt before we have your logo.

Please make checks payable to **JOSHUA'S BUDDIES**.

SEE YOU ON THE 21st of JUNE!