

Gone But Not Forgotten

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The Great Battle Against AIDS

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We're Incorporated!

On July 20, 2004. The Great Battle Against SIDS incorporated in the State of California. The Great Battle Against SIDS was organized to provide a variety of support to families after the death of an infant to Sudden Infant Death Syndrome (SIDS) & Other Infant Death (OID). By providing financial assistance related to final arrangements, families are able to concentrate on grieving and finding HEALTHY ways to deal with the emotions they face. By providing support groups & peer contacts, families are able to communicate with others who have dealt with infant death, providing a basis for a HEALTHY approach to handling grief. By providing resources & references to professionals, The Great Battle Against SIDS is able to help those who have turned to alcohol, drugs, and other immediate health issues, in order to avoid the emotional burdens associated with infant loss. The Great Battle against SIDS strives and will continue to strive to support families in all aspects of life after the death of an infant, toddler or young child.

By offering such support we hope we can decrease the number of families destroyed by the loss of a young child, infant, & toddler. The services provided at no charge by The Great Battle Against SIDS will help reduce the need for state & county funded mental health programs.

Submit Newsletter submissions to:
Editor@BattleSIDS.org
Fax: (909) 794-3725
or Mail them to:
The Great Battle Against SIDS
Attn: Editor
2257 A Mentone Blvd.
Mentone, CA 92359

Our Programs!

Angels In Need!

The Angels In Need Program's purpose is to assist families with burial, funeral & cremations costs after the death of their infant due to SIDS (Sudden Infant Death Syndrome) or other natural death that does not have a funeral program. This program will help eliminate the tremendous cost that can increase the emotional stress associated with infant death. Reducing the financial burden can dramatically increase the chances of a family dealing with their grief in a "healthy" way.

Support Group Meetings

Trained volunteers facilitate support group meetings for SIDS/OID families, offering the opportunity for new parents to see that they are not alone. Currently 1 group meets on the 1st Thursday of each month. When additional meeting arrangements are acquired, additional meetings will be made available. Anyone interested in participating in a support group meeting, should contact The Great Battle Against SIDS at (909) 794-3725 Please be advised that if you are in an area that has an active support organization, The Great Battle Against SIDS will forward your information and request to the organization covering your area.

Peer Support!

Specially trained Sudden Infant Death Syndrome (SIDS) or other infant death (OID) parents and other family members are on call to help new SIDS/OID families with the loss of their infant. Level 1 (trained, giving support) Peer Support Contacts (PSC), must have lost their child at least 1-year prior to receiving training or providing support. Level 2 PSC (those receiving support) should be qualified to receive support immediately after the child's death. Peer support is an essential portion of The Great battle Against SIDS support system.

SIDS & SIDDT Is there a connection?

Recent research was released regarding a genetic connection to SIDS. We're excited to announce that there will be an article in the US News & World report regarding this issue & they've interviewed Melissa in regards to issue. My point of view remains that it is great research, and we welcome the additional testing on the general population. Below you can read the full press release from TGEN.

Researchers Identify Gene for a Primary Form of Sudden Infant Death Syndrome (SIDS)

Why some infants die suddenly is no longer a mystery

PHOENIX, July 19, 2004 – Scientists at the Translational Genomics Research Institute (TGen), Phoenix, Arizona, and the Clinic for Special Children, Strasburg, Pennsylvania, have found the genetic basis for one form of sudden infant death syndrome (SIDS). The researchers have named the newly described form as sudden infant death with dysgenesis of testes, or SIDDT. The finding, released this week on-line by the journal Proceedings of the National Academy of Sciences could provide new insight into the inexplicable, sudden deaths of some 3,000 infants a year in the US.

SIDS has long been a catchall term for infants that die unexpectedly of unknown causes before their first birthday. By discovering a gene linked to some of these deaths, a team of researchers led by Dr. Dietrich Stephan, director of neurogenomics at TGen, and the paper's senior author, has begun to expose the distinct genetic causes behind these deaths.

"This is one of the first genetic sub-classifications of SIDS," Stephan said. "And it's going to be helpful in offering parents answers for sudden infant deaths, recognizing predisposition early, and hopefully saving a number of these babies."

The researchers first identified patients with SIDDT in a small Old Order Amish community in central Pennsylvania. Over two generations, nine families from this community had lost twenty-one infants to this sudden death syndrome. This familial clustering suggested a genetic basis for the syndrome. All infants with SIDDT died before 12 months of age of abrupt cardiac and respiratory arrest. While many of these infants underwent testing at major medical centers, no abnormalities were found. Males with SIDDT may also have underdeveloped testes. Females appear to be normal and have normal female hormones in blood and urine. Despite these differences, male and female infants with SIDDT died suddenly at the same age.

The researchers analyzed the DNA from four of these infants, along with their parents, siblings, and extended family members. Using Affymetrix (Nasdaq: AFFX) SNP arrays — which examine 11,555 single letter, or nucleotide, variations in the genome known as single nucleotide polymorphisms — the researchers narrowed the location of the disorder to a region on chromosome 6. By correlating the genes known to reside in the region with their clinical understanding



were carriers of the alteration. Although several other genes are known to be associated with SIDS, this is the first gene identified which causes a primary form of SIDS.

"This study provides new insight into how the nervous system is regulated and highlights the benefits of close collaborations between researchers, physicians, and the patients they care for," said Dr. Erik G. Puffenberger, Laboratory Director at the Clinic for Special Children, the paper's first author.

The discovery also demonstrates the rapidly increasing speed of modern medical research. The mapping and identification of the gene was performed in less than two months from start to finish. According to the physicians at the Clinic for Special Children, SIDDT is a new disease that has never been described before. The alteration in TSPYL can affect the neurological system and cause sudden death, and in males can also affect the reproductive system. According to Stephan, the relationship of TSPYL mutations or polymorphisms to SIDS in the general population will be studied next. Future work will examine the effects of this gene on the normal control of breathing and heart rate in otherwise normal, premature infants. The gene may be used as a diagnostic marker and to develop treatments.

"This collaboration between the Clinic for Special Children, Translational Genome Research Institute (TGEN), and Affymetrix is an important example of how modern genetic knowledge can, and should be, used to help solve medical problems," said Dr. D. Holmes Morton, Director of the Clinic for Special Children.

Our Shop!

We've been working hard to update our shop! There are now several hundred items to choose from! Every dollar we earn from the shop is used to support our organization! We'd like to

[Http://cafeshops.com/battlesids](http://cafeshops.com/battlesids)



There are currently 387 products in The Great Battle Against SIDS shop! Items include jr. spaghetti tank tops, camisoles, women's tank tops, men's sleeveless tees, jr. baby doll t-shirts, golf shirts, value shirts, white t-shirts, fitted t-shirts, ash grey t-shirts, organic cotton t-shirts, women's t-shirts (in white & pink) green t-shirts, yellow t-shirts, ringer t-shirts (available in 3 colors), jr. raglans (available in 3 colors), baseball jerseys (available in 3 colors), athletic jerseys, long sleeve t-shirts, jr. hoodies, sweatshirts, hooded sweatshirts, kids t-shirts, infant/toddler t-shirts, bibs, journals, framed prints (available in 3 sizes), posters (available in 3 sizes), greeting cards, postcards, calendars, stickers (available in 3 sizes), coffee mugs (available in 3 sizes), tote bags, messenger bags, ball caps, license plate frames, teddy bears, lunch boxes, tile boxes, tile coasters, Frisbees, wall clocks, aprons, buttons, magnets, steins, & mouse pads!



Our first fundraiser!



If you would like to participate in our bulb fundraiser, please visit
<http://battlesids.org/bulbs.PDF>

Please email or call Melissa if you plan on participating!
Melissa@BattleSIDS.org
(909) 794-3725



If you would like to make a donation please make the check payable to:
The Great Battle Against SIDS

Mail your check & the information on the right, to:

The Great battle Against SIDS
Attn: Daniel Clements
2257 A Mentone Blvd.
Mentone, CA 92359

Sorry at this time we can not process credit card donations.

PLEASE NOTE:
The Great Battle Against SIDS 501(c)
(3) status has been filed but is currently pending.

Your Donations Keep Our Programs Going!

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Phone

In Memory Of:

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