

# Ignorance still kills

Jesse Cause maintains its advocacy of group B strep awareness

by Patricia Alexander

On Dec. 2, 1999, the Ventura County Reporter published an investigative report about a highly preventable bacteria called Group Beta Streptococcus (GBS). The story noted the advocacy of parents whose newborns had had calamitous and sometimes fatal contact with GBS. Group B strep, according to the Centers for Disease Control and Prevention (CDC), was the leading infectious killer of newborns, yet most people had never heard of it.

Ventura-based recording artist Chris Keith and his wife Shelene were among the many uninformed when Jesse, their newborn boy, nearly died of a GBS infection. Now five, Jesse is a survivor after having undergone three brain surgeries. He also has a permanent drainage shunt running from head to chest.



Jesse Keith (right) is the inspiration for The Jesse Cause, founded by dad Chris (left) and mom Shelene to promote awareness of the volatile group B strep bacteria. Photo by Jim DiModica

Like many parents, the Keiths were stunned when they discovered that one in three pregnant women carry the GBS bacteria, which generally manifests no symptoms. They were furious once they found they might have been spared their trauma if Shelene had been administered a reasonably simple insurance-approved test and \$10 worth of antibiotics during labor.

The Keiths' anger moved them to found The Jesse Cause, a non-profit organization that seeks to publicize the dilemma. They focused on educating parents-to-be to request GBS testing and treatment. They created and distributed an informational pamphlet, garnered radio, television and newspaper coverage and told their story to national community groups—all in a search for the reasons that pregnant women weren't being tested for GBS.

For many reasons—among them the lack of testing—statistics on GBS are unreliable. At minimum, several thousand babies a year are infected. Some will recover completely; some will be left with lifelong handicaps such as mental retardation, blindness, deafness, brain damage and cerebral palsy; and some will die.

At one time, the explanation for the lack of testing seemed to be that medical professionals were deeply divided about its cost effectiveness and feared that treatment might eventually develop into antibiotic resistance. Furthermore, 1996 CDC protocols did not clearly recommend testing. One physician who attended a CDC medical conference on GBS that year confirmed a growing suspicion: Economics, not medicine, drove

creation of the conference's GBS guidelines. In a move to protect its membership, the American College of Obstetricians and Gynecologists (ACOG) blocked the otherwise unanimous consensus for universal testing, fearing lawsuits from GBS-positive women never tested or treated.

The CDC eventually altered its 1996 guidelines by concluding that testing pregnant women for GBS was equally acceptable under standard "risk-based" strategies, which involve administering antibiotics only to women in labor who showed risk-based factors for infection: fever, premature labor, membranes broken for 18 hours without delivery or a prior GBS pregnancy.

Like many women, Shelene Keith did not carry any of these risk factors. Indeed, preliminary studies showed that no such factors were present in about 50 percent of GBS-positive women. The only way to determine that these women were GBS-positive, then, was to test them.

However, without years of supporting documentation, this logic did not prevail. Many well-meaning but busy obstetricians simply accepted the ACOG declaration that risk-based protocol was more than adequate. The doctors who read the CDC document, however, usually chose to test.

The Reporter's story was picked up for a segment on CBS' 48 Hours, with the Keiths among three GBS families interviewed. The Keiths were thus successful in raising awareness of GBS—however, the guidelines for treatment remained ambiguous.

To support the theoretical benefits of universal testing, the CDC launched an eight-state surveillance study. After a year and a half, and at the persistent urging of The Jesse Cause, the CDC called a news conference on Nov. 1, 2001, to present its findings.

At that meeting, ACOG agreed to support universal testing. And on Aug. 16, 2002, the CDC released new guidelines recommending that all pregnant women be tested at the 35th to 37th week of pregnancy. Ironically, fear of liability will now ensure that doctors do test for Group B strep.

"The CDC," Shelene Keith said, "told me that the only reason they were able to fund the study was because of the media attention that was created from The Jesse Cause and GBS parents nationwide, proving that people who are motivated enough, who are trying to save babies, do have the power to change the system."

This July marks the third annual National GBS Awareness Month. The Jesse Cause hopes to raise money for radio and TV public service announcements to this effect.

On Nov. 16, 2002, the FDA approved a reliable "rapid test" for GBS, developed by the Canadian company IDI. The test can be performed in labor and delivery and will be available by late March, enabling women who have not been under a doctor's care or who go into labor prematurely to be tested.

According to Baylor University College of Medicine researcher Carol Baker, great strides have been made in the development of a GBS vaccine. Supported by the National Institutes of Health, the studies indicate the vaccine could be safely given to pregnant women at 30 to 32 weeks of pregnancy as well as to healthy women considering pregnancy.

But the vaccine may have no means for production and distribution, because pharmaceutical companies traditionally do not find vaccines profitable. Moreover, the new rapid test requires hospitals to purchase a machine and for personnel to be trained in its use. And it will take months for the new guidelines to be put into place and to ensure that the testing is done correctly and accurately. Each state department of health, depending on whether it includes an interested official, will play a major role in how thoroughly this is done.

Meanwhile, ignorance still kills, as doctors are often too busy to explain the complexities of GBS. The Keiths are working with philanthropic organizations and with corporations such as IDI to fund the publication and distribution of their informational brochure.

And despite the changes in guidelines, several factors undermine awareness of GBS. Although it is infectious, it is not a reportable disease. It still does not appear as an entry on most states' infant birth or death certificates, and most doctors' orders for infant care do not include GBS procedures.

The new CDC guidelines do not raise awareness of the fact that GBS can cross into the placenta at any time during pregnancy. Thus, GBS-positive women with planned Caesarean sections will not be given antibiotics unless they demand them.

GBS-positive women need to be wary of invasive procedures such as forceful or frequent cervical exams and internal fetal monitors. And women who have trouble carrying to term or who have previously tested positive for GBS should request testing early in pregnancy as well as in the prescribed 35 to 37 weeks.

The Keiths believe the ultimate message learned from Group B strep is that women must regard themselves as consumers who cannot expect the medical community to provide perfect care in an imperfect world. Pregnant women, especially those who have tested positive for GBS, still need to assume their own advocacy and to educate themselves about every existing precaution. Only then will parents have the best possible opportunity to raise babies who are healthy and whole.

*The Jesse Cause can be reached at (877) 425-8427.*

*The Reporter's cover story can be found on the Jesse Cause web site at [www.thejessecause.org](http://www.thejessecause.org)*