

Meningococcal Disease

*A closer look at the deadly, devastating disease
that could affect your baby*

Brought to you by: MomCentral and Meningitis Angels
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- Aside from injuries and neonatal complications, meningococcal disease is among the leading causes of preventable infant death in the U.S. Approximately 50-60% of these cases are vaccine preventable
- Recent CDC estimates reveal that meningococcal disease incidence is three to seven times higher in infants under one year old than in any other age group, and the highest risk for meningococcal disease is during the first seven months of life
- Approximately 1 in 16 infants who contract meningococcal disease will die from it
- There are more deaths from meningococcal disease each year than there are from pertussis, measles, mumps, rubella and rotavirus disease - all infections which infants currently receive vaccinations for.



Meningitis Angels

Frankie Milley, Founder/National Executive Director

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Web sites

www.Meningitis-Angels.org or www.ProtectInfantsNow.org

Contact Frankie Milley at FMilley@aol.com

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The last time I held my baby.

Meningitis Angels

Facts About Meningitis

Meningococcal disease is devastating, and it affects infants and teens in particular. We hope these facts will help you see how important it is to prevent this disease. The CDC has already taken huge steps in preventing this disease in teens and young adults. Now they have an opportunity to prevent the same meningococcal disease in infants.

What is Meningococcal Disease?

- Meningococcal disease is a leading cause of meningitis (an infection of the membrane around the brain and spinal cord) and sepsis (a life-threatening bloodstream infection)
- There are five groups of meningococcal bacteria that are responsible for causing most of the disease. They are C, A, Y, B and W135. Four of these groups are vaccine preventable (C, A, Y and W135)
- Each year, approximately 1 in 7 people who contract meningococcal disease will die from it
- The disease starts with non-specific flu-like symptoms, progresses rapidly and aggressively and can kill in as few as four hours, making it a very difficult disease to diagnose and treat
- Of those who survive, 1 in 6 will suffer limb amputations, paralysis, seizures, strokes, hearing loss, blindness, organ damage, severe scarring, brain damage and more.

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WE
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Let your voice be heard: Visit www.ProtectInfantsNow.org to learn how you can raise your voice with ours and ask the CDC to make the right decision by encouraging them to recommend adding this lifesaving vaccine to the infant immunization schedule. We cannot neglect the opportunity to protect our children and try to eliminate as many cases of this disease as possible.

Infants are the Most Vulnerable Among Us

They cannot stand up for themselves, and so it is our job to protect them. Every child deserves a healthy start. That is why the Centers for Disease Control and Prevention (CDC) recommends that infants be vaccinated against many diseases that threaten their health and their lives.

But one deadly disease continues to cause intense devastation among infants and their families: Meningococcal disease, one of the most common causes of meningitis and sepsis. This disease is one of the leading causes of preventable death in infants. Recently a vaccine was approved by the FDA to prevent meningococcal disease in infants as young as 9 months. The CDC has recommended it for use in infants at high risk. This vaccine and recommendation brings us one step closer to eliminating this fast moving, deadly disease that kills and maims children. Pending FDA review and approval there are more vaccines for infants as young as 2 months on the horizon. In order for infants to receive these vaccines, the CDC must make a recommendation for their use in infants.

Right now the CDC is in the process of gathering public opinion on this issue and in the near months ahead making the important decision of whether to recommend that all infants receive this lifesaving vaccine and others as they become available in order to move towards eliminating this terrible disease. We hope you will take the time to learn about meningococcal disease, preventative health measures, and of course, the vaccines that can prevent this disease.

Thank you for helping us to Protect Infants Now.

One Child is Too Many to Risk!!!

About Meningitis Angels



Meningitis Angels is a national non-profit organization founded in memory of Ryan Wayne Milley, the only child of Bob and Frankie Milley. Ryan's life was taken at age 18, as a result of meningococcal meningitis/meningococemia.

Hundreds of families from across America and around the world make Angels one of the largest meningitis organizations globally.

Meningitis Angels educates the public, health professionals, child care facilities, schools and universities on not only meningitis but other vaccine preventable diseases and the preventions including vaccines, though personal stories, our educational brochures, posters and videos.

Meningitis Angels is dedicated to the support of victims of bacterial meningitis and their families. While helping families cope with the loss or care of a family member they also offer some hands on support for those children affected with bacterial meningitis.

Sadly, Meningitis Angels continues to grow in honor and memory of those whose lives were affected or taken by these deadly, preventable diseases.

If you had meningococcal meningitis as an infant or toddler or your child had meningococcal meningitis as an infant or toddler please contact Frankie ASAP at fmilley@aol.com.

We need your help!

Patient / Advocate Bios & Stories

Frankie Milley

Founder and National Executive Director, Meningitis Angels
Conroe, Texas

Frankie Milley started Meningitis Angels in 1998 after the passing of her 18 year-old son, Ryan, from meningitis. Since then, she has continued to be an active meningitis prevention and awareness advocate. She helped write Texas Senate Bill 31, which helped Texas become the first state in the country to educate students of all ages on bacterial meningitis, and she has continued this work in 17 other states. Along with other parents across the country, Milley helped to establish meningitis vaccine recommendations for college freshmen and in recent years served on the Centers For Disease Control's steering committee for meningococcal meningitis vaccine recommendations.

Milley speaks around the nation at medical and patient advocacy conferences, policy making hearings and legislative hearings on the importance of disease prevention through immunizations. In addition, she is a member of the Texas Department of Health Immunization Stakeholder Working Group (TISWG) and has served on its adolescent immunization sub-committee.

Articles written by and about her have been published in medical magazines, newspapers and web journals around the U.S. She has been honored by Governor Rick Perry of Texas for her work on immunizations and was most recently honored by the Houston Area Immunization Partnership for her public service in promoting vaccinations. She has been named Hometown Hero by her community for her work on children's health and received letters of thanks from several governors across the country. Milley and Meningitis Angels have also received letters of recognition from both Presidents Bush and Obama.



Patient / Advocate Bios & Stories

Boone Family

Ethan Boone, son of Chris and Heather Boone, contracted meningococcal disease at 7 months
North Carolina

Ethan was born a healthy, happy little baby. He was a head of his age in development. Ethan was only 7 months old when meningococemia struck his life and took him from perfect health to complete debilitation.

Currently, Ethan is in a very compromised health state. Due to his resulting limb amputations, he can't get food for or feed himself; he can't bathe himself or go to the bathroom alone. If there were ever an emergency at home, he would not be able to escape by himself. Sadly, he may never have prosthetics due to the severity of his amputations. He also risks injury to his hips and leg stubs because of the way he has to get around now. He lost most of his beautiful face – he has to have continual reconstructive surgery which is very painful and stressful to him and his parents.

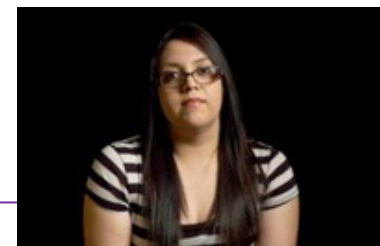
Ethan is now almost 4 years old, and asks why he doesn't have feet and arms. He has realized the severity of his facial damage and does not want people looking at him or taking his photo. Ethan has to have care 24 hours a day, 7 days a week. His life has been changed by this disease.

In the months ahead, pending FDA approval, a vaccine could prevent this from happening to your infant. As Meningitis Angels Team Leaders, Ethan's parents are working hard to make sure ACIP will recommend this vaccine when it becomes available. You can help; please visit www.ProtectInfantsNow.org and sign the petition.



Yecenia Manzano

Meningococcal disease awareness
advocate; mother who lost infant
daughter Bella at 5 months
California



Yecenia's daughter, Bella, was born a beautiful, healthy baby. She was always happy and smiling. Unfortunately, at just 3 1/2 months old, she contracted meningococcal meningitis. At around midnight, she developed an unrelenting fever. She never cried; she just slept. In the early morning hours, she took a bottle and began projectile vomiting and was then taken to the emergency room. Within a few hours, she developed pin-prick-sized spots on her forehead and face. Shortly after, Bella went into a coma.

The remainder of Bella's short life was spent in a hospital on life support. In the days and weeks that followed, over 60% of her body had gangrene and became petrified. This skin had to be removed and replaced with skin from a cadaver. Most of her face fell off on her pillow, and her little arms and legs were to be amputated. However, she died before they were able to. Bella's mother watched her beautiful baby rot away from this horrible disease. At a little over 5 1/2 months old, Bella died in the hospital. This beautiful baby girl suffered a horrific death.

There was no vaccine for Bella's age group to prevent meningococcal meningitis ; however, pending FDA approval, there will be soon. Yecenia is now working hard as a Meningitis Angels Team Leader to make sure ACIP will recommend this life saving vaccine when it is available.

Please join Yecenia and visit www.ProtectInfantsNow.org to sign the petition.

Patient / Advocate Bios & Stories

Julian Junior Sparks

Son of Brittani Crumlich; died of meningococcal disease at 14 months

Julian, born on May 23, 2008 was a perfectly health and happy baby – always smiling and making faces to get others to laugh. That summer, Julian’s mother took him on vacation to Virginia and Pennsylvania to visit family. One morning during their trip, Julian woke up with a slight fever; he had trouble walking and was pulling on his ear. Later, Julian started vomiting, which prompted Brittani to call the pediatrician, who advised her to take him to the hospital.

When they got to the hospital, Julian’s fever had gone down, and there were no signs that stood out to the doctors. When Brittani changed Julian’s diaper, she noticed a purple rash and 5 minutes later, it had spread to his arms, chest, back, feet – all over his body.

The doctor diagnosed this as meningitis, and soon after Brittani’s son went into septic shock. The nurses performed CPR on Julian for 2 hours – longer than they were obligated to – because he was fighting so hard... until he could not fight it anymore.

Julian lost his life to meningococcal disease on August 15, 2009.



Brittani Crumlich

Meningococcal disease awareness advocate; mother who lost infant son to the disease, Virginia Beach, Virginia



After the loss of her 14 month old son Julian Junior Sparks in August of 2009, Brittani Crumlich became a member of Meningitis Angels, a national advocacy organization dedicated to meningitis disease education and prevention.

Originally from Colorado, Brittani has since relocated to Virginia Beach and gave birth to another child in March 2011.

Brittani is now committed to spreading meningococcal disease awareness to help save parents from having to go through what she experienced with her infant son 2 years ago.

Website Links

Meningitis Angels

<http://www.meningitis-angels.org/>

Protect Infants Now (PIN)

<http://www.protectinfantsnow.org/>

Direct Link to PIN Petition

<https://www.petitionbuzz.com/petitions/protectinfantsnow>

Meningitis Angels PSA

<http://www.youtube.com/watch?v=SQ2qLQ7F8TU>

Logos

Meningitis Angels



Protect Infants Now



Disclosure

Should you choose to write about meningococcal disease and its devastation among infants, we request the inclusion of the following disclosure:

“I participated in a campaign on behalf of MomCentral and Meningitis Angels. This campaign was made possible in part through support provided by Novartis Vaccines. A small donation to [INSERT CHARITY] was made in my name from MomCentral as a thank you for participating. All opinions in this posting are 100% my own.”

Thank you!