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When the Word “Meningitis” Darkens the Room

Meningococcal Meningitis Awareness

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This paper is intended for a general audience- but mostly parents- including both people who have no information about this disease and those who have recently become familiar with it. The intent is to inform about what meningococcal meningitis can do, how fast it happens, and the emergent necessity for its recognition. Those who are interested can go on to read about how and why the process occurs.

Purpose:

The purpose for this body of work is to promote knowledge and make parents (and others) aware of meningococcal disease, what to look for, and the importance of immediate health care. Also for those here in the Northwest to be aware that there is no vaccine for the strain in our geographical area, but the other four strains are preventable- this becomes relevant during travel and for college kids roving about the country, or the world. The purpose also includes providing information to enable the reader to make an educated decision about whether or not to vaccinate against this disease.

Section 1

STORIES:

This section shows that this disease happens to real people- not just someone who's the cousin of an uncle's best friend who's married to so and so and related to that one guy twice removed. It's personal. In the words of Lynn Bozof, a mother who lost her son to meningococcal meningitis, "It's rare, but it happens."

Section 2

NEED TO KNOW:

Factual knowledge about the disease, what it can do, who it effects, how you get it, how (for most strains) to prevent it, and how important it is to get help immediately.

Section 3

WHAT YOU MIGHT EXPECT:

This section includes some of the things that might happen when a person gets to the hospital and is under suspicion of having contracted meningitis, some tests, and treatments. It also describes some of the complications that can occur from having meningitis.

Section 4

AFTER THE FACT:

A description of what a family goes through after the disease has imposed itself on their lives; however, it is not intended to be all inclusive.

Section 5

HOW THE BACTERIA WORKS:

For those who want to know, this section outlines what the organism that causes the disease is, how it works, and why it's so nasty. For some, understanding the disease can help to provide comfort and lessen fear by de-alienating the process and helping to put catastrophe in perspective.

Section 6

KNOWLEDGE:

Knowledge is power; we need all the knowledge we can get to combat this disease.

When the Word “Meningitis” Darkens the Room

1 THE STORIES

A nurse in the pediatric department at Mercy Medical Center in Roseburg, Oregon, stated to her patient’s father, Blake Wise, that meningococcal meningitis is the scariest disease a child can acquire. On the other side of the door the three year old patient, my niece, Jasmine Wise, was playing video games and looking forward to an end to her five-day hospital stay. Jasmine was lucky. Meningococcal meningitis is a disease that progresses very quickly- it can kill in a matter of hours.

On the afternoon of Saturday, February 9, 2008, Jasmine had a spotty rash over her body. She had been playing all day, carrying on like her normal happy, healthy self. Her dad wasn’t worried. He assumed that she had just come down with Chicken Pox. Brianna, a seven month old baby who lives in the same household, had been ill and had vomited that day. The next morning, Sunday, February 10th, Brianna had a couple of spots on her body; an hour later she was covered in them. This was the first sign that something was really wrong, that these two girls were suffering from something beyond a minor childhood ailment.

Brianna's mother, Amber Davids, rushed her to the nearest hospital about twenty miles away. By the time she reached the emergency room, Brianna was almost completely purple. Blake had taken Jasmine in to be evaluated as well. Both girls were immediately treated for meningococcal meningitis, and Brianna was put on a life flight to Doernbecher Children's Hospital in Portland, Oregon. She has been in the hospital for five weeks as of this date, March 16, 2008; three of which were in the pediatric intensive care unit. There is not yet a projected date for her release.



This is Brianna on February 16, day 7.



This is Brianna again on February 29, day 20.

Brianna has already had several surgeries and faces amputations. She has had a tracheotomy to aid in her breathing and a surgery to temporarily remove her intestines in order to relieve pressure inside her abdomen. Her intestines were left outside her body, wrapped in gauze and laying on her abdomen, for several days while doctors waited for pressure inside her body to go down enough to avoid organ damage. She has gangrene on her fingers and toes- the tissues have completely died and have turned black- because the infection in her bloodstream has choked out most of her circulating oxygen so that none was available to those tissues. She will lose her left foot, the toes on her right foot, and three fingertips on her left hand.

It has been an emotional journey for all of us in Brianna's family. The impact of her illness has struck me with such force that I find it very difficult to describe. It is impossible to watch this happen to a child and not feel the pain and anguish as if it had happened to your own son or daughter. In the beginning Brianna didn't have much hope; her medical team had given her only a two percent chance of survival. Today, we know she will live her life without one foot and a few fingertips. But her life, her love, her smile, all that she is and ever will be, continue. And her mother will not have to live without her.

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Each family experience I find assaults me with tears, concern and urgency. A video from the National Meningitis Association, [Getting It: A Disease](#), promotes vaccination against meningitis and includes several personal accounts of the tragedy resulting from meningococcal disease. One account is that of McKenzie Hartwig: The last time her parents saw her was when

they dropped her off for her first day of college. "That day we hugged and kissed her goodbye. I never, ever thought it would be the last time we would see her alive," said her mom, Laurie Hartwig. McKenzie, one of the college's star volleyball players, had gone to a tournament and had become ill. The school contacted her parents, and they rushed to the hospital. Meningococcal meningitis took McKenzie's life four hours before her parents could reach her. Her father, Ken Hartwig, said that, "The suddenness of it was what I had a hard time dealing with...There was not any time to say goodbye" (Getting It). The McKenzie Meningitis Foundation has been created in honor of her life.

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Ashley's story: Ashley Lee came home from college for the weekend and wasn't feeling well; her family thought that she had the flu. Throughout the day she worsened to the point that she could no longer walk. At the hospital the doctors didn't know what was wrong; they wanted to treat her for dehydration and release her. But then she developed a rash on her forehead and back. Ashley's father demanded that she be taken to another hospital that was 90 minutes away. During the drive the swelling and bruising that marked her body increased dramatically. Ashley's father says, "It's really hard to explain how rapidly this moves. Minutes count, not hours, minutes actually count." Ashley's parents had requested a vaccine for meningitis prior to her going off to college and had been denied by the physician. The vaccine was too hard to get, too expensive. They were lead to believe that "It really wasn't that big a deal." It was a big deal; Ashley lost three fingers and her left foot, but nearly her life (Getting It).

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Evan Bozof was a pre-med student. At the start of his spring break from college he came down with a severe headache that sent him to the hospital. While there he was checked for meningitis- it was ruled out. The doctors thought he just had a virus. His mother, Lynn Bozof, wonders that this disease can “take a healthy person and kill them within hours.” Evan’s brother, Dr. Ryan Bozof, has a face that shows deep sorrow and his voice shakes as he recalls the moment that he learned of his brother’s condition. He said, “It’s something you can’t even comprehend. All of a sudden you’re faced with death.” It took weeks for Evan to lose his life; he was in a coma with machines keeping him alive. Evan had spoken about a person who had come down with meningitis a few years before but the family took no action regarding his concern. Now they look back and say, “It’s rare, but it happens” (Getting It). After the death of her son, Lynn Bozof founded the National Meningitis Foundation.

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Every case was devastating so quickly. As the images cover my monitor, one after another, of these victims with blackened fingers and toes, purple arms and legs, I recall in my mind those same markings on Brianna’s tiny body. Looking at her face you would think she’d been in a car wreck. Move your eyes down to her legs, and you would see what look like the legs of a burn victim. But we keep telling ourselves *she’s lucky*. She lived; the infection did not take her life. That’s what we will continue to repeat when she’s in kindergarten learning to write without her fingertips. It’s a small price to pay for her precious life. If Brianna’s mom had waited any longer, hours or even minutes, her story would be much different.



This is what a meningococcal rash looks like.

Photo from the Meningitis Research Foundation.
25 Feb. 2008 <<http://www.meningitis.org>>



The "Glass Test" shows that the spots of the meningococcal rash do not blanch when pressure is applied.

Photo from the Meningitis Research Foundation.
25 Feb. 2008 <<http://www.meningitis.org>>



A little girl after her fight with meningococcal meningitis.

Photo from the Ellie May Fund
7 Mar. 2008 <<http://www.twynkamschool.com>>



A 15 year old boy showing his amputation after the disease.

Photo from Channel 11 News, Houston, Texas
7 Mar. 2008

<http://www.khou.com/news/local/stories/khou051004_c_d_uocise_meningitis.c1b47763.html>

2 WHAT YOU NEED TO KNOW

This is a rare disease that most know nothing about and the prevention of meningococcal death lays in *immediate* recognition of this disease. Early treatment, even the morning after a nighttime onset, may not be fast enough. Nancy Snyderman, M.D., petitions that "It almost takes an overreaction of sorts to suspect [meningitis]" (Getting It). It is so important to know what to look for.

Meningococcal meningitis is a bacterial infection of the cerebrospinal fluid that surrounds the brain and spinal cord (Centers for Disease Control). The infection causes swelling of the membranes that contain this fluid, resulting in severe complications. Meningitis has a viral form that is not as serious and usually does not require treatment, but the bacterial forms require immediate medical attention and aggressive antibiotic therapy. Spinal meningitis is another name for the same disease and can refer to any of the bacterial or the viral strains. Most cases occur in the fall, winter, or early spring (Lewis et al. 1518).

Signs and symptoms of meningitis, described by Marilyn Hockenberry, pediatric nurse practitioner and author of Nursing Care of Infants and Children, differ slightly from one age group to another. In newborns, the disease is particularly hard to diagnose; for one thing, babies can't tell us when something is wrong. The signs of meningitis in this age group tend to be non-specific; they appear the same as other illnesses and differ from the signs in older children. An infected newborn may refuse feedings, have difficulty sucking, and may vomit or have diarrhea. Hypothermia, fever, jaundice, drowsiness, bluish skin coloring, and weight loss may also occur. The most indicative signs, a bulging soft spot on a baby's head (at the fontanel) and seizures show up late in the disease process (Hockenberry 1678). A red spotty rash is specific to meningococcal meningitis; it does not occur in other strains, and it can occur in any age group. If you see a rash like this, to test whether or not it indicates meningococcal meningitis, use the glass test (see box on page 6). Find a clear drinking glass and press it to the skin. If the redness of the spots does not blanch or fade when the pressure is applied, it may be meningococcal meningitis (Meningitis Research Foundation). Seek *immediate* medical attention.

Infants and children between the ages of 3 months and 2 years who are infected show the signs listed above; the bulging fontanel will show up earlier in this age group. These kids will also often have a high pitched cry and doctors may look for neurological signs that indicate infection around the brain (Hockenberry 1678).

Kids over the age of two, teenagers included, show more sudden and perceptible signs at the onset of the disease. They usually experience fever, headache, and vomiting

accompanied by sensory changes including sensitivity to light, confusion, hallucinations, and seizures (Hockenberry 1678). This is the age group, along with adults, that demonstrates the classic meningitis sign: a stiff, sore neck. If the illness progresses untreated, the infected person's head may extend severely backward, and he or she may enter a coma.

Meningitis can cause death, brain damage, the loss of fingers, toes, hands, feet, arms, legs, internal organs, hearing, and sight. These severe, lasting effects are why this disease is so important. In America, about 3000 cases occur annually, of whom 10 to 12 percent, between 300 and 360 people, die (National Meningitis Association). In contrast, during the 2006 to 2007 flu season in the United States, 23,753 cases of the flu were reported to the World Health Organization. About 7.5% of these cases, 1781 cases, resulted in death (Centers for Disease Control). If left untreated, every strain of bacterial meningitis has a death rate of nearly 100% (Lewis et al. 1518).

Although anyone can get meningitis, those most vulnerable are infants, young children, adolescents, college freshmen, military recruits, refugees, and household members in contact with an infected person (National Meningitis Association). The age group between 1 month and 5 years of age claims ninety percent of reported cases of bacterial meningitis; the disease is "a significant cause of illness in the pediatric age-groups" (Hockenberry 1677). College kids who live in dorms are at a greater risk because of close communal living conditions, irregular sleep habits, and poor eating habits. Also, of them, many have immune systems that don't work at their peak (McKenzie Meningitis Foundation). The stressful lifestyle associated with college life tires out the body and can decrease the effectiveness of the immune system.

Those who are vulnerable may be attacked by one of five different types of disease causing *Neisseria meningitidis*, four of which are preventable by a vaccination with boosters every three years (The Meningitis Centre). This vaccine is not widely available and it is expensive. It's up to the consumer to demand it from the healthcare system, to be proactive and persistent in order to get it. In the United States, those who live in the great Northwest have more to worry about than those in other areas of the country because the type of *N. meningitidis* found in the Northwest does not have a vaccine (Richardson 57). This type has a different make-up than the other four and scientists have not yet found a way to combat it.

N. meningitidis is airborne and most commonly enters the body through the nose. It is spread from another person infected with these bacteria, often by a sneeze or a cough. A person can unknowingly carry *N. meningitidis* in their nose without ever getting sick; these people are called carriers. Audrey Unrau, pediatric physician at The Children's Clinic of Legacy Meridian Park Hospital in Tualatin, Oregon, says that as many as 25% of the general population are carriers of this bug. To get sick, you have to make direct contact with the infected material from the carrier because *N. meningitidis* cannot live outside a body.

3 WHAT YOU MIGHT EXPECT

After being admitted to the hospital on suspicion of meningococcal meningitis, a patient will often be put into an isolation room to prevent the spread of the bacteria to others. The family members and anyone else who may have been in contact with the infected person will undergo prophylactic, or "just-in-case", antibiotic treatment.

For a definite diagnosis, the physician will order blood tests and a spinal tap, or lumbar puncture, to be done. The spinal tap involves a needle being inserted into the area of the spine that holds the cerebral spinal fluid. There is no danger of being paralyzed because the spinal cord ends above the point of needle entry (Lewis et al. 1487). The fluid will be drawn out of the spine into a syringe and it, along with the blood drawn, will be tested for the presence of any of the bacteria that cause meningitis.

Doctors might also look for two neurological signs: the Brudzinski sign and the Kernig sign. To evaluate the Brudzinski sign the child lies on his back and brings his chin toward his chest, if his legs come up involuntarily at the knees and hips, the test is positive for the Brudzinski sign. He may also express pain with the neck movement. To test for the Kernig sign the child lies on her back and raises one leg upward, bent at the knee. The test is positive if she feels pain or resists when the leg is kept elevated and straightened out (Hockenberry 1678).

Increased pressure inside the skull is the cause of many of the complications resulting from meningitis. The complications depend on the location of the increased pressure and what nerve or nerves are compressed. Some possibilities due to nerve compression are blindness, deafness, and facial paralysis. Most of these are correctable after recovery. Direct pressure on the brain can cause residual brain damage, coma, and death (Lewis et al. 1519).

Meningococcal sepsis, or meningococcemia, is one of the most serious complications and has a very high mortality rate (Hockenberry 1678). Meningococcemia occurs when the blood becomes infected with the bacteria. Most of those who develop this complication die. Waterhouse-Frederichsen Syndrome, a more serious complication, occurs when meningococcemia occurs rapidly and severely. It results in shock, hemorrhage of both kidneys,

bleeding into the skin, and disseminated intravascular coagulation, or DIC (Hockenberry 1678). DIC results in uncontrollable internal hemorrhage and cannot be stopped until the meningitis is brought under control (Lewis et al. 729). According to Hockenberry, the death rate of those who come down with Waterhouse-Friderichsen syndrome is as high as 90%; it requires immediate treatment and intensive care for survival (1678).

Another complication one might see is SIADH, Syndrome of Inappropriate Antidiuretic Hormone. It occurs when swelling around the brain effects the pituitary gland, causing it to release too much antidiuretic hormone. This causes the kidneys to reabsorb most of the liquid that would normally be part of the urine, putting it back into the bloodstream. With too much water in the blood, children end up with a range of symptoms from nausea and irritability to convulsions and personality changes. Like Waterhouse-Friderichsen syndrome, SIADH will disappear when the meningococcal infection is brought under control (Hockenberry 1716)

4 AFTER THE FACT

The suddenness and severity of this illness causes serious emotional impact on the family of the sick, especially if the sick person is a child. Parents often feel guilt for not having recognized the disease sooner and may assume responsibility for its progression. As with Jasmine and Brianna, there are so many “What if” questions. What if we had noticed sooner, what if we hadn’t notice at all, what if it happens again, what if? There is no end to the possibilities. It is important to remember, as a parent, that some things are just out of your control. This disease is so monstrous that despite the very best efforts, circumstance is a major variable in how this disease plays out. Hockenberry states that the outcome “depend[s] to a

large extent on the age of the child...by the type of organism, [on] the effectiveness of therapy...and whether [or not] it occurs as a complication of another illness or injury" (1677-1678). Parents and family members need assurance that they took action in responsible manner, that it's a good thing they sought care when they did. The aggressiveness of this disease is something that no one can expect.

Such rapid movement through tragedy overwhelms everyone involved in the infected person's life. It's astounding when there are only hours or minutes between perfect health and possible death. The sudden possibility or even likelihood of death leaves us with a sense of hopelessness and grief, there is no transition period, no moment of understanding and acceptance until this disease has already turned our lives upside down.

5 HOW THE BACTERIA WORKS

What makes this disease so nasty? Meningococcal meningitis is caused by a bacterial pathogen called *Neisseria meningitidis* which is a gram-negative diplococcus (Leboffe 147). A diplococcus is a pair of round bacterial cells that are joined together. Being gram-negative, each bacterium has a special outer layer containing a toxin called lipopolysaccharide, abbreviated as LPS. This toxin is released upon cell death and causes endotoxic shock in the infected person (Richardson 43). As a matter of medical intervention, fighting this disease isn't just a matter of killing all of the bacteria inside the person because that itself could cause the person's death. Life supportive therapy must be included to ensure that endotoxic shock does not claim the life of the infected person.

In addition, these bacteria produce a capsule that covers the whole organism (Leboffe 147). The human body has an efficient immune system that recognizes foreign bodies and attacks accordingly. This capsule made by *N. meningitidis* is made from a sugar that camouflages its presence from the immune system because sugars are not foreign to the human body. The result is widespread bacterial infection prior to the immune system's recognition of the invasion. The capsule, along with spike-like appendages called pili, also helps the bacteria to stick to the surface of the nasal membranes (Leboffe 147). While remaining hidden from the body's immune system, each single bacterium reproduces and the body's population of *N. meningitidis* doubles every 20 minutes (Getting It).

N. meningitidis is an aerobe, meaning that it requires a large amount of oxygen to live. In order to meet its oxygen requirements, these bacteria produce a substance that breaks down red blood cells and steals the oxygen from the blood for its own use (Leboffe 147). Some strains even have a substance on their surface that disguises the bacteria to appear as if they are red blood cells. *N. meningitidis* usually enters the body through the nose and the underlying blood vessels of the nasal membranes give the bacteria a perfect opportunity to diffuse into the blood stream. Once introduced into the bloodstream, the bacteria move on to the cerebral blood supply in the brain and cerebral spinal fluid where the meningitis disease process begins (Hockenberry 1677).

Once these bacteria penetrate into the cerebral spinal fluid it infects the meninges, the linings around the brain and spinal cord. The disease of meningitis originates with inflammation of the meninges causing pressure on and obstructed blood flow to the brain. The

increased pressure on the brain, depending on which areas are impacted, can result in deafness, blindness, learning disabilities, and other complications previously described.

There are twelve different types of these bacteria and five cause meningococcal disease: A, B, C, Y, and W153 (World Health Organization). As mentioned earlier, four of these are preventable by vaccination. Type B is the strain that dominates meningococcal meningitis outbreaks here in the Northwest and has no vaccine available in the United States. The difference is that the type B *N. meningitidis* has a different capsule from the others (Richardson, 57). A vaccine exists for it in New Zealand but has not been approved for use in the United States. Other vaccines for this strain are being researched in Cuba, Scotland, and Norway (National Meningitis Association).

6 KNOWLEDGE

While we wait for a vaccine that prevents all types of meningitis, it is essential to know about this disease, to arm yourselves and everyone you know with the knowledge necessary to combat the tragedy of its occurrence at the most basic level: recognition. No one should have to endure the losses that the victims of meningitis face. The lives Brianna Davids, McKenzie Hartwig, Ashley Lee, and Evan Bozof are all lives that will be in the back of my mind for the rest of my life. My most heartfelt wish is that I never hear the name of your child or family member mentioned when the word “meningitis” darkens the room.

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