



Maine Immunization Program 2011 Annual Conference

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Learning Objectives

- Understand the difference between vaccines required for school vs. vaccines recommended by AAP, ACIP.
- Be aware of the influence that providers have over first time parents.
- Realize the implications to a family when proper vaccines are not administered.



Brianna's Journey....

My whole life, all I ever wanted was to have children. There is no doubt in my mind that God put me on this earth to be a mother. When I became pregnant with my first child after over a year of trying, I was ecstatic. Right away, I was focused on having the healthiest pregnancy possible. I signed up for prenatal water aerobics, took my folic acid supplements, and ate only the recommended foods. When our baby, girl Brianna entered our lives the world stopped. And all that mattered was our beautiful baby girl. I breastfed exclusively for the first year of her life, I took the time to make all of her own baby food. And we went to every well check with the best pediatrician in our area. We were fortunate that our doctor was certified in internal medicine as well as pediatrics. So we felt fortunate that we already had a relationship with a fantastic doctor that had three kids of his own. And my husband and I believed strongly in vaccinations.

At every well check, we went through the “shots” and we always asked about what she was getting and what the side effects may be. I was the type of thorough mother that always asked questions. So, let me repeat that again....

We believed in vaccinations.

So how did our life take such a drastic turn...

Brianna was a very healthy baby. At two and a half years old, Brianna came down with a common cold. It progressed into an ear infection in which we took her to the pediatrician’s office to get an antibiotic.

A few days passed, and Brianna continued to get worse. We went back to the ped’s office where she was diagnosed with pneumonia.

He decided to take an aggressive route with IV antibiotics as an out-patient through our local hospital. After two days of iv antibiotics, I became very concerned. On our third trip to the hospital for the final dose, I stated that I was not leaving until I talked to our pediatrician. Brianna continued to get worse was very lethargic and could barely lift her head to take medicine. I knew something was terribly wrong. The benefit of a small community was our ability to see our own pediatrician at the hospital...on a Saturday. The nurse was able to get in touch with him by phone right away. He ordered fluids, nebulizer treatments, and an x-ray and told the nurse he would be there as soon as he could. By the time the x-ray was read, and our pediatrician showed up we were whisked away by ambulance to the pediatric intensive care unit at Eastern Maine Medical Center with our ped in tow.

He rode in the ambulance with me and did not leave my side until he personally spoke with the Doctor at the PICU. Brianna had a collapsed lung and had developed an epyema, which was fluid that accumulated through out her pleural cavity, literally shifting major organs to the side. The very first question the PICU doctor asked me was “is she up to date on her immunizations”. “Of course!” I replied. They immediately inserted a chest tube to start draining the fluid and put her on oxygen. They started the course of running tests as there were concerns of her kidney function as well as many other complications. It was a nightmare, a very complicated nightmare.

Today I am going to give you the fast version.

After two days of Bri on oxygen, fluid draining from the chest tube, and constant pain, they decided to do a CT scan. The CT scan showed a good size mass on her left lung. The PICU doctor was very concerned and stated she may not get better until the mass is removed. He felt it was a CCAM, which is a congenital mass that could have been there since birth. And Bangor did not have a pediatric surgeon. In the meantime, Brianna at age two and a half, was in pain and having severe anxiety attacks if Mommy even left the room. She wouldn't eat, she wouldn't talk, she wouldn't get out of bed. Not to mention, I had an 18 month old son at home being bounced around with family. But with no pediatric surgeon on staff, we were rushed by ambulance to Barbara Bush Children's Hospital in Portland. Brianna could not even make the trip without being heavily sedated. We were immediately greeted by the pediatric surgeon.

Within 30 minutes, we were rushed down to surgery. At the last minute, the surgeon came out and told us he was canceling the surgery. He agreed with the PICU doctor that the mass was the CCAM, however, the pediatric radiologist felt that it was a necrotizing pneumonia in which would clear up on its own over time.

Let the roller coaster begin.... So the surgeon ordered a PICC line be inserted the next day with the hopes that the aggressive long term iv antibiotics would clear the mass up on its own and if it did require surgery she would need to be stronger. So, we spent the next week and a half at Barbara Bush Children's Hospital. I never left the hospital. We met with specialist after specialist and still had very few answers. Brianna still would not eat and was on t-pan.

The goal was to get her stronger, eating on her own and send her home with a home health nurse visiting once a week. They wanted to give her one month before they repeated the ct-scan to check the size of the mass. Our pediatrician had given me his personal cell phone number to me and stayed in touch to talk about medical procedures. It was a relief to have him to consult with as the doctors in Portland were overwhelming. They talked a different language than the doctors in Bangor and there were so many of them....the surgeon, the pediatric infectious disease doctor, the pediatrician at the hospital not to mention dozens of nurses in and out. Our life was crazy. I was staying at the Hospital around the clock and my husband was staying at the Ronald McDonald House. Our eighteen month old son was still bounced around with family almost two hours away.

After a full two weeks of being in the Hospital, we were released with restrictions. Brianna came home with a PICC line in which I became trained to become her “nurse” and administer medications. She was not allowed to be in daycare, so I took a leave of absence from my job to care for her.

The home health agency came once a week to change the dressings and draw blood as they were monitoring her blood counts very carefully.

The next several months were very stressful. Brianna continued to spike very high fevers and her blood counts would go off the charts. The world would stop, we would pack up our son and send him with family and we would head it back down the highway. We were back and forth to our regular pediatrician. He would send us back to Portland for a few days, they would send us back home still with no answers.

The PICC line became so irritated, they had to remove it early. They went back and forth between thinking the mass was a CCAM and thinking it was a necrotizing pneumonia. Nobody was certain what the mass was, and nobody agreed. She endured four CT scans with iv contrast and dozens of x-rays, and multiple blood draws. Every CT scan sent her over the edge. It got to the point, they would have to sedate her to sedate her. It was extremely agonizing to watch as a mother. I lost 30 pounds and had missed several weeks of work. The medical bills were mounting...ambulance rides, PICU care, ct scans. The stress was taking a toll on my marriage as well. I was home with Brianna all day taking care of her, and my husband, who felt so helpless being at work all day, tried to have all the answers even though he was not the one going to every appointment.

Through it all, our pediatrician was there for my family. He would talk to doctors and relay the medical jargon back to us in English! When Brianna had such anxiety over doctors, it was our pediatrician that drove to her day care to check her out in a non-threatening environment. But with still no answers five months later, our pediatrician sent us to Boston to meet with a pediatric infectious disease specialist. With our first phone consult with Boston we were given a list of materials we would need to bring to the appointment. The first item was her shot chart. Fast forward to my professional life... The day before our trip to Boston I was at kindergarten screenings. I was helping the nurse check shot records when I realized this certain shot kept showing up on the children's health records, but I had never heard of it. Then my nephew came in and he did not have it on his shot record.

I went to get Brianna's shot record in my purse all packed for the next day's appointment. To my astonishment, she too, was missing the pneumococcal vaccination. What?? How could this be?? I had this sick feeling in my stomach as I researched the vaccine... The research stated... Pneumococcal bacteria can infect the sinuses and inner ear. It can also infect the LUNGS, blood, and brain, and these conditions can be fatal. Pneumococcal conjugate vaccine (PCV) is used to prevent infection caused by pneumococcal bacteria.

Then I called our ped's office, in which the receptionist told me that that PCV was not given there. There only explanation was the doctor simply did not believe in giving it. I tried not to think about it, and tried to think there was no correlation. I loved my doctor, he had been so good to us, there must be a good reason. How did I not know about this? In denial, I tried to forget about it.

We went to Boston, in which they put Brianna through another series of tests. They then referred us to a pediatric pulmonologist. Almost a year later, we repeated x-rays and met with him. The first thing he told us is that the mass appeared to be improving slightly. Which means the mass was more than likely dead lung tissue caused by a severe pneumonia. The good news came when he announced that your lungs grown until your nine years old, which means there was plenty of time for new lung tissue to regenerate. And this time, when he asked me if she was up to date on her immunizations “I said yes, but she has not had PCV”. He literally fell off his stool. He tried to remain professional, but he could not hide his emotion. He said “What do you mean?”.

And I said “Well, we just found out that our doctor did not give that shot at his office.” He looked me in the eye, and said “you do know that if she had received that vaccine, she probably would not have received a pneumonia of this magnitude.” I was devastated. My husband and I did not speak the entire ride home. How could this happen to us? We did everything right. How could our doctor make that decision and not even inform us? We just assumed she was getting all of the vaccinations she needed. And what if I walked into the Pediatric Intensive Care Unit the first day and said “she has not had PCV.” Would that have prevented the confusion of not knowing what the mass was? Would they have suspected necrotizing pneumonia from the beginning? I just went through the year from hell...and it all could have been prevented??

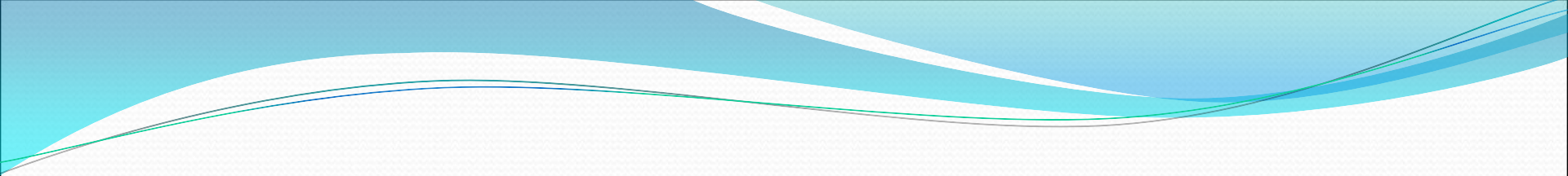
A year from hell, and still dealing with the aftermath. Remember I told you that Brianna was on heavy duty antibiotics for a very long time with the PICC line. At the hospital they were giving her two different kinds of antibiotics at the same time, and she was discharged with antibiotic by iv as well as an antibiotic by mouth. I am sure all of you medical people can guess what happened next. Brianna developed a resistance to antibiotics.

The following spring, Brianna complained her ear hurt. She was diagnosed with an ear infection (remember she never had chronic ear infections as an infant or toddler). Three different antibiotics and nothing touched a simple ear infection.

She ended up having to have surgery to have tubes put in her ears. And you can imagine what surgery did to her....yup sent backwards in which she had severe anxiety. And now she was getting older, and much smarter. When we arrived at the Hospital, she would not get out of the car. I had to crawl in the back of the van and drag her out of the car and carry her in the hospital kicking and screaming. It was a nightmare. Brianna was not an obstinate child and to see her so terrified of hospitals and doctors was heart breaking. So the tubes worked for about a year. The next spring, she developed a random ear infection again. Once again, nothing would touch it. Back trying to get into specialists. Back in to surgery we went. Another traumatic experience for Brianna in which they had to sedate her to sedate her.

She came out of surgery so hysterical, they handed me a barf bag and sent me on my way. But every day, in the back of my mind, I am thinking what if she gets strep throat, what if she gets a very serious infection that nothing will touch?

Currently, Brianna is six years old and just finishing up kindergarten. We have been fortunate.....very fortunate. I truly feel that we dodged a bullet that winter. I am here today because our situation went wrong in so many different ways. If I can prevent just one family from going through what we went through, then it will all be worth it.



First, let's talk about Vaccine "Requirements" in Maine. It is important for parents to understand the difference between recommended vaccines and required vaccines. It's important for parents to understand that doctors are able to make their own rules when it comes to vaccinating children. YOU are your only child's advocate. You must understand everything there is to know about vaccinations to keep your child safe.

DAYCARE ENTRY

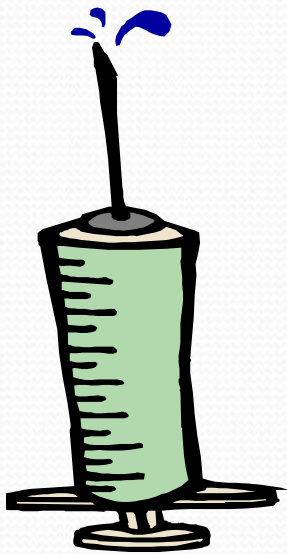
**So, this is where one loop hole also happened with our experience. Our daughter was enrolled in a licensed day care. I asked why it was never picked up that she did not have PCV. That is when I found out that day care providers are not trained to look at the shot records to see what is there and what may be missing. When the State comes to inspect their facility, they simply have to prove there is a shot record – it does not matter what shots are listed on it, could list one shot, could list them all. Nobody ever checks it. So is that really a daycare requirement...if nobody enforces it

Vaccine



“Requirements”

in Maine



Daycare Entry

****Daycares are not trained to read shot records!**

- Diphtheria/Pertussis/Tetanus (DTaP)
- Measles/Mumps/Rubella (MMR)
- Poliomyelitis (IPV)
- Hemophilus influenza Type B (Hib)
- Hepatitis B (HepB)
- Pneumococcal conjugate (PCV)
- Varicella

Elementary School Entry

- Diphtheria/Pertussis/Tetanus (5 DTaP)
- Measles/Mumps/Rubella (2 MMR)
- Poliomyelitis (4 IPV)
- Varicella (1 dose required)

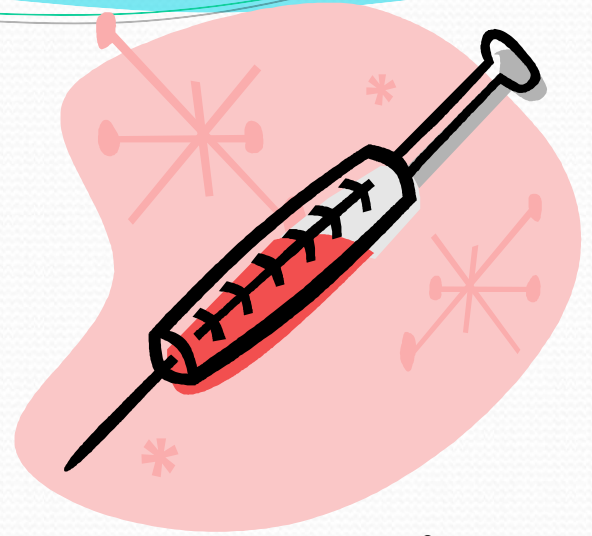
Postsecondary School Entry

- Diphtheria/Pertussis/Tetanus (DTaP)
- Measles/Mumps/Rubella (MMR)

Additional Immunizations that are RECOMMENDED

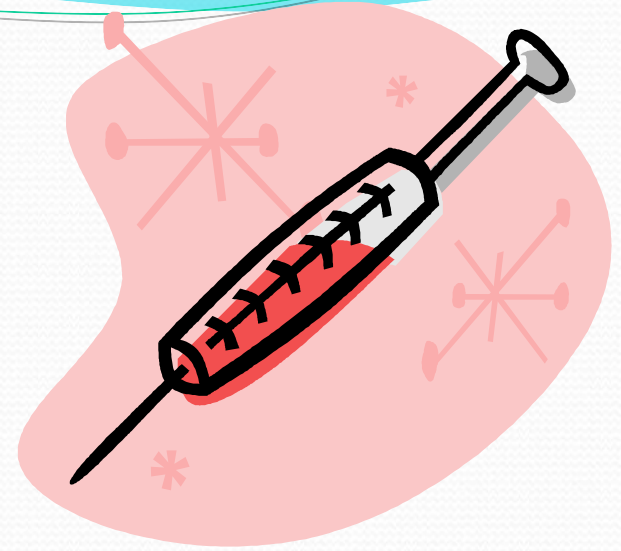
- Influenza vaccine on a yearly basis
- Hepatitis B
- Hib (Hemophilus Influenza B)
- Meningococcal vaccine
- Pneumococcal vaccine
- Hepatitis A
- Human Papilloma Virus (HPV)

My Plea....



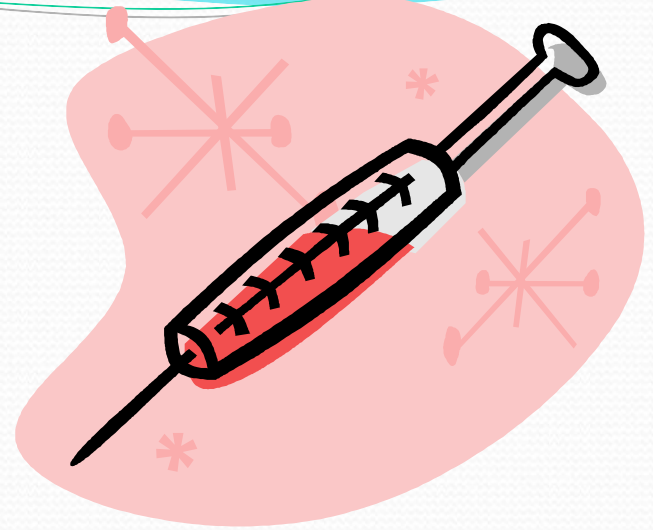
- Learn as much as you possibly can about the vaccinations that are offered. Knowledge is power!

My Plea...



- Get involved!
- Support legislation that provides vaccines free of charge for all Maine children!
- Maine Immunization Coalition

My Plea...



- Providers...please understand the influence you have over first time parents.



Thank you!

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