



## International Vasa Previa Foundation

Pregnancy. The months and weeks leading up to the birth of a child are some of a woman's most exciting times, filled with the anticipation, hope and joy of giving birth to a new life. When all goes well during the pregnancy, labor and delivery, and a beautiful healthy baby comes into the world, a miracle takes place. But what happens when a condition goes undetected or is misdiagnosed and in 95% of cases the outcome is fatal? Even in today's modern medical world of advanced technology and well-trained clinicians, oversights occur. This is especially true when it is a rare condition like vasa previa and is not part of the normal pre-natal screening.

Vasa previa, reported in 1:3000 pregnancies, is a condition in which fetal blood vessel(s) from the placenta or umbilical cord cross the entrance to the birth canal, beneath the baby. The condition has a high fetal mortality due to rapid fetal hemorrhage resulting from the vessels tearing when the cervix dilates, membranes rupture, or if the vessels become pinched off as they are compressed between the baby and the walls of the birth canal.

Vasa previa has been detected during pregnancy as early as the 16th week. Infant death from vasa previa is preventable when diagnosed prenatally.

The International Vasa Previa Foundation (IVPF) was established in January 2001. It is a result of the [Vasa Previa e-mail group](#), which was founded on June 25th, 2000 by parents who've experienced a vasa previa pregnancy.

The IVPF agrees that vasa previa can, but should not be, a devastating complication of pregnancy. Despite its severity, it is commonly unrecognized by women, midwives, and sometimes even obstetricians. Despite the technology existing to detect vasa previa prenatally, it is rarely diagnosed prior to the onset of labor and sometimes, fatal decisions are made during labor and delivery.

The goals of the IVPF are to increase awareness about vasa previa and to adjust the medical rules and protocols worldwide in such a way that fatal outcomes associated with vasa previa can be prevented.

The IVPF would like to take this opportunity to enlighten you further about this condition and try to prevent the fatal outcome by reaching the medical community and general public. Attached is additional information about the IVPF as well as stories from our members and their children, both the vasa previa survivors and the vasa previa angels. Please take a moment to visit our press room at <http://www.vasaprevia.org>

In the event you would like more information on vasa previa, please contact us and we will connect you with one of our members and/or spokesperson physicians.

We look forward to the day when vasa previa is no longer a fatal condition. After all, it only takes a moment to diagnose life.

Regards,

Victoria Goldstein IVPF PR  
Committee

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# International Vasa Previa Foundation

## **History**

The **International Vasa Previa Foundation (IVPF)** was established in January 2001. It is a result of the [Vasa Previa e-mail group](#), which was founded on June 25th, 2000 by parents who've experienced a vasa previa pregnancy.

## **Vision**

Creating a world without vasa previa deaths while supporting those whose lives have been impacted by it.

## **Mission**

To raise awareness about vasa previa and to adjust the medical rules and protocols in such a way that fatal outcomes associated with vasa previa can be prevented.

## **An Avoidable Tragedy**

The International Vasa Previa Foundation agrees that vasa previa is an avoidable tragedy and should not be a devastating complication of pregnancy because it can be detected during pregnancy with use of transvaginal sonography in combination with color Doppler. Despite its severity, it is commonly unrecognized by women, midwives, and many obstetricians. It is rarely detected during pregnancy and often, inadequate decisions made during labor and delivery result in fetal mortality rates estimated to be as high as 95 percent.

## **Donations**

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# International Vasa Previa Foundation

## Fact Sheet

<b>Cause</b>	<b>Vasa previa</b> occurs when fetal blood vessel(s) from the placenta or umbilical cord cross the entrance to the birth canal, beneath the baby. Vasa previa can result in rapid fetal hemorrhage (occurs from the vessels tearing when the cervix dilates or membranes rupture) or lack of oxygen (if the vessels become pinched off as they are compressed between the baby and the walls of the birth canal). The aberrant vessels result from velamentous insertion of the cord, bilobed or succenturiate lobed placenta.
<b>Symptoms</b>	Vasa previa can be asymptomatic but can also present with sudden onset of abnormally heavy or small amounts of painless vaginal bleeding in the second or third trimester of pregnancy. Source of blood should always be investigated to determine whether the blood is maternal or fetal.
<b>Incidence</b>	Rarely reported, occurs in 1:2500 to 3000 births with a fetal mortality rate estimated to be as high as 95 percent if not diagnosed prenatally. (1-2)
<b>Prognosis</b>	When properly diagnosed prenatally, prognosis of survival is very good. The fetal mortality rate is very low when an elective C-section is performed after fetal lung maturity is adequate.
<b>Ante partum Diagnosis</b>	Changing current routine obstetrical ultrasound protocols to include checking the placental cord connection for velamentous cord insertion during all routine obstetrical ultrasounds is recommended (preferably with color Doppler). All suspected cases of velamentous cord insertion, placenta previa, low-lying placenta, multi-gestational pregnancies, and multi-lobed placentas need to be checked for vasa previa with transvaginal color Doppler ultrasound. (3) Vasa previa can be detected during pregnancy as early as the 16th week with use of transvaginal sonography in combination with color Doppler. (4) Infant death from vasa previa is preventable if diagnosed prenatally.
<b>Warning Signs</b>	Vasa previa might be present if any (or none) of the following conditions exist: low-lying placenta (may be caused by previous miscarriages followed by curetting of the uterus (D&C), or uterine operations, which causes scarring in the uterus), bilobed or succenturiate-lobed placentas, velamentous insertion of the cord, pregnancies resulting from in-vitro fertilization or multiple pregnancies. (5-6) Vasa previa bleeding is painless. Other OB or birthing bleeding complications are not necessarily painless.
<b>Treatment</b>	When diagnosed prenatally, treatment plans could include the following: use of tocolytes to stop all uterine activity; bedrest; no sexual intercourse, vaginal exams, lifting, heavy straining during bowel movements (use of stool softeners); hospitalization; fetal monitoring; regular ultrasounds to monitor progression of vasa previa; determination of source of bleeding (either fetal or maternal); amniocentesis to access fetal lung maturity; steroid treatment to develop fetal lung maturity; and most importantly, elective cesarean delivery early enough to avoid an emergency but late enough to avoid complications of prematurity. When not diagnosed prenatally, aggressive resuscitation complete with blood transfusion for the infant if necessary must be planned for and/or expected. (7)
<b>For More Information:</b>	<a href="http://www.vasaprevia.org">http://www.vasaprevia.org</a>

## **REFERENCES**

- (1) Vago T, Caspi E. Antepartum bleeding due to injury of velamentous placental vessels. *Obstet Gynecol* 1962;20:671-5
- (2) Quek, SP, Tan KL. Vasa praevia. *Aust NZ J Obstet Gynaecol* 1972;12:206
- (3) Gianopoulos J, Carver T, Tomich P et al. Diagnosis of vasa previa with ultrasonography. *Obstet Gynecol* 1987;69(3 Pt 2):488-491
- (4) Meyer WJ, Blumenthal L, Cadkin A et al. Vasa previa: Prenatal diagnosis with transvaginal color Doppler flow imaging. *Am J Obstet Gynecol* 1993; 169:1627-1629
- (5) Evans GM. Vasa praevia. *Br Med J* 1952;2:1243
- (6) McAfee CHG. Placenta praevia-A study of 174 cases. *J Obstet Gynaecol Br Emp* 1945;52:313
- (7) K.O Oyelese, M. Turner, C. Lees and S. Campbell. Vasa Previa: An Avoidable Obstetric Tragedy. *Obstet and Gynec Survey* 1999; Volume 54, Number 2:138-144



## International Vasa Previa Foundation

### **What the experts have to say about Vasa Previa**

*Vasa previa is a rare condition; however it is often a lethal one. For years we have tried to get the general ObGyn community to appreciate this condition and to realize that it can result in the death of an otherwise totally normal infant. The tragedy is even greater because the pregnancy is often entirely uncomplicated, and demise of the baby occurs just at the very end of pregnancy when the parents are looking forward with excitement and expectation to the birth of a healthy baby. Our attempts to have more frequent screening performed have been criticized because it is felt that the condition is rare, and indeed it is. However, very few other conditions carry such a high mortality in a previously normal fetus. The arguments have been that it is prohibitively expensive to screen for vasa previa using ultrasound and that it requires a reasonable degree of skill to make the diagnosis. As such, it is not currently the standard of care to look for vasa previa. Nevertheless, we have identified a second-trimester low-lying placenta as an important risk factor, and recommend targeted sonographic screening with transvaginal sonography and color Doppler for vasa previa in women whose placentas have been identified as low-lying in the second trimester, regardless of whether the placenta remains low-lying at term or not. Other women who should be screened for vasa previa include those with placentas which have succenturiate lobes, women with multiple pregnancies, and those with pregnancies resulting from in-vitro fertilization. Because survival of the baby depends almost entirely on prenatal diagnosis, this strategy for selective screening, followed by elective cesarean delivery, will help reduce the mortality from vasa previa..*

**Yinka Oyelese, M.D**

**Georgetown University Hospital, Washington, D.C.**

**October 2001**

*Vasa previa is a very rare but well known and well respected condition in the area in which I practice, obstetrics. The advances in ultrasound have greatly aided in the diagnosis and management of this problem. The biggest problem is to identify the patients that are at risk for this condition. The way that we discover these rare abnormalities of placentation is through routine screening ultrasounds at 18-20 weeks. If there are low lying placentas or placenta previas, we then examine the lower uterine segment with doppler flow. We then routinely send these patients to an ultrasound center for confirmation. Also, any patients with abnormal bleeding in the 2nd and 3rd trimesters need appropriate evaluation for this condition. The fetal mortality rate if undetected varies considerably from 33%-66%. The fetal mortality rate when an elective c-section is performed when fetal lung maturity is adequate is very low.*

**Frank A. Frenduto, M.D.**

**Private Practice OBGYN, Durham, North Carolina**

**October 2001**

*I believe it is really important to heighten the awareness of physicians and sonographers doing obstetrical ultrasound to the potential clues to this dangerous condition. I also believe vasa previa is more common than currently believed. In my practice alone, I have diagnosed five patients with vasa previa in the last year. I urge my students to look for the clues of vasa previa. If a placenta is bilobed, regardless of location, or if there are unusual blood vessels at the placental periphery which could be a clue to a membranous umbilical cord origin, then scans using colorflow imaging over the internal os (entrance) of the cervix should be done to exclude vasa previa.*

**Harris Finberg, M.D.**

**High-risk obstetrical radiologist in Phoenix**

**November 2000**

*Of course I support your goal for vasa praevia. Unfortunately, I fear that this is a problem that will continue to evade even the most vigilant of sonographers unless they actively look for vasa praevia. Additionally, I am lucky that all the ultrasound machines in my unit have colour Doppler. Unfortunately, this is not the case in many hospitals world wide, making the detection of vasa praevia even more difficult.*

**Basky Thilaganathan**

**Director, Fetal Medicine Unit**

**St.George's Hospital Medical School London June 2001**



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## Glossary

**amniocentesis** - (also commonly referred to as "amnio") is a common prenatal test. During the procedure, an ultrasound device is used to determine the baby's position, and then a long hollow needle is introduced to withdraw amniotic fluid from around the fetus. (The baby is not touched.) The particles of the baby's sloughed-off skin cells floating in the water are then tested in a lab for fetal abnormalities. Results are usually back in 8-10 days. Amnios are also used to determine fetal lung maturity when preterm labor has been recommended.

**antepartum**- relating to the period before parturition (action or process of giving birth); before childbirth

**bilobed placenta** (latin name: placentae bilobata) - To be classified as bipartite or tripartite the two or three lobes of a placenta should be separated by a membrane and be of equal or near equal size. There is no certain information on how multilobed placentas are formed. A bipartite placenta in one pregnancy may be followed by greater-than-expected frequency of bipartite placenta in the next pregnancy. This raises the possibility that some multilobed placentas have genetic origin. The umbilical cord most often inserts into the membranes between the two lobes of bipartite placentas but in about one-third of cases it inserts into the larger of the two lobes. The two clinical manifestations of multilobed placetas most often cited are bleeding in the first trimester of pregnancy, and a failure of one of the lobes to separate at delivery with consequent postpartum hemorrhage.

**color Doppler ultrasound**- used to measure the velocity of blood flow. Doppler ultrasound can be used to listen to the fetal heart beat, examine the fetal heart for effects and estimate placental blood flow. This special type of ultrasound shows different rates of blood flow in different colors blue and red on a monitor in real time. One color goes from the placenta to the baby and the other one from the baby to the placenta. This way the location of the fetal vessels can be detected and the suspected diagnosis vasa previa can be confirmed or rejected.

**low placenta** - early in pregnancy, the zygote (fertilized egg) implants in the uterus and forms a placenta. Implantation that occurs low in the uterus may result in a placenta that is close to or covers the cervical os (birth canal). Most low-lying placentas migrate (move) during later pregnancy towards the fundus (top of the uterus) and away from the cervix. A low placenta has four degrees of severity:

1. Low-lying placenta: The placenta is implanted low in the uterus close to the cervix but the edge of the placenta does not reach the cervical os.
2. Marginal placenta previa: The edge of the placenta is at the margin of the cervical os.
3. Partial placenta previa: The cervical os is partially covered by the placenta.
4. Total placenta previa: The cervix is completely covered by the placenta.

**multi-gestational pregnancies** – a pregnancy of twins, triplets and beyond

**Ogita-test** - test used to determine presence of fetal blood. The test will detect fetal hemoglobin down to a concentration of 20%

**placenta previa** an abnormal implantation of the placenta at or near the internal opening of the uterine cervix so that it tends to precede the child at birth usually causing severe maternal or fetal hemorrhage

**steroid shots** – administered when fetal lung maturity needs to be accelerated for early delivery prescribed when continuing pregnancy to term would compromise baby's healthy outcome.

**succenturiate lobed placenta** - A succenturiate (accessory) lobe is a second or third placental lobe that is much smaller than the largest lobe. Unlike bipartite lobes, the smaller succenturiate lobe often has areas of infarction or atrophy. The risk factors associated are advanced maternal age, primigravida, proteinuria in the first trimester of pregnancy, and major malformations in the fetus. The membranes between the lobes in such placenta can be torn during delivery, and the extra lobe can be retained after rest of the placenta has been delivered, with consequent postpartum bleeding.

**tocolytes** Denoting any pharmacological agent used to arrest uterine contractions: often used in an attempt to arrest premature labor contractions.

**transvaginal sonography:** Small device which is used within the vagina that utilizes high frequency (5.0-7.5 MHz) transducers, which offers improved resolution of normal anatomy and pathology in the female pelvis when compared to the transabdominal approach. This advantage is particularly apparent in the obese patient, the patient with a retroflexed/retroverted uterus and in identification of anatomy too small to be visualized transabdominally or that which cannot be palpated on manual exam.

**Trophotropism theory** (Theory developed by Dr. Harris Finberg, M.D.) trophotropism in placental tissue can be compared to the tendency of a plant to lean towards the sun to get the light it needs to survive. Since the lower segment of the uterus is not as nourishing as the upper segment, the placenta will grow upwards to reach more nourishing tissue.

**vasa previa-** (latin name: Vasa Praevia) Vasa previa is a rarely (1:3000) reported condition in which fetal blood vessel(s) from the placenta or umbilical cord crosses the entrance to the birth canal, beneath the baby. The condition has a high fetal mortality rate (50-90%). This can be attributed to rapid fetal exsanguination resulting from the vessels tearing when the cervix dilates, membranes rupture or if the vessels become pinched off as they are compressed between the baby and the walls of the birth canal.

**velamentous insertion of the cord** - Normally, the veins of the baby run from the middle of the placenta via the umbilical cord to the baby. Velamentous insertion means that the veins, unprotected by Wharton's jelly, traverse the membranes before they come together into the umbilical cord.



# International Vasa Previa Foundation

## VASA PREVIA STORIES

I would like to tell you about my “miracle” baby. I would be very surprised if you had ever heard of the condition, “vasa previa (VP)”. It is a little known condition that occurs in 1:3000 pregnancies. The fatality rate is 50 to 90%. I was told that if undetected before birth, the fatality rate is 95 to 100%. And this begins my story.

In June 1996, my husband and I found out we were expecting our second child. We were thrilled! My first pregnancy was textbook, so I didn't foresee what we would go through.

When I was eight weeks into my pregnancy, I noticed some spotting. Since this did not happen at all in my first pregnancy, I made an immediate appointment with my doctor. An ultrasound was done. My doctor informed me that everything was fine, except that there was an extra lobe on the placenta. (I have since discovered that this is one of the primary indicators of VP.) The doctor informed me that the only complication would be if they didn't know about it during delivery and all the placenta did not deliver. She said that since we knew, there would be NO complications. She did, however, follow-up with subsequent ultrasounds during my term. The lobe seemed to move, disappear, reappear, etc., but that should still cause no problem. I still felt very good about this pregnancy and did not worry at all.

At 36 weeks, I awoke one morning to a LARGE amount of blood. I immediately woke my husband and while my brother came to stay with our two year old, Bob rushed me to the hospital. We saw a resident doctor in fairly short order and another ultrasound was performed and the belly strap was put on to keep track of the baby's heartbeat This ultrasound showed that the baby was breech. An obstetrician was called in because of the bleeding. The nurses wanted me to get up and walk, but every time I did, the bleeding increased. They did not seem to think that the bleeding was a problem. They were more concerned with the fact that the baby was breech. The resident voiced his opinion to us; saying that he thought a caesarean should be performed that day. My family doctor thought that a C-section was unnecessary, but that they should induce within the next day. The obstetrician came in, looked at one ultrasound very quickly and left I was kept in the hospital over night and Bob took the next day off thinking that I would be induced. My doctor called the next morning and said that the obstetrician wanted me to go home and take it easy until labor started on its own. Him being a specialist, I really thought he knew what he was talking about (By this time, the bleeding had stopped.)

I went home, happy to be back with my husband and son. I called my place of employment and told them that I would have to go on disability until the baby came as per doctor's orders. They were great about it the doctors told me to stay on bed rest, except for going into the hospital every two days for a bio-physical profile (an in-depth ultrasound.)

Things went fine for 12 days. Then, on the morning of Jan. 27, 1997, I once again awoke to profuse bleeding - bad enough that I initially thought that my water had broken. I was much calmer this time, due to the casualness that the medical staff seemed to be treating this with, but I did prepare to go to the hospital right away.

When we arrived at the hospital, it was exactly as it had been the previous time. The same resident was on duty, the nurses set up the ultrasound and the belly strap was used. Nurses would periodically check in to check the heart rate, but other than that, we were just left there for two hours. I asked if anyone had called my doctor and was told that they could not call her until something happened (what exactly, I'm not sure.)

I finally sent my husband off to work, thinking he should save his time off for when the baby did come and this looked like it was going to be a repeat of our previous visit. As Bob was walking away from the room, I felt a gush and though my water broke. I screamed for Bob to come back. He called a nurse and we were all excited until we saw that my water did not break, but it was blood. The nurse tried to find a heartbeat, but couldn't. She called the resident in and he also could not find a heartbeat All of a sudden, they shoved Bob out of the way and said they were taking me to the OR. The last thing I remember is a bunch of doctors and nurses standing over me with scalpels.

When I awoke, Bob and my doctor were standing directly over me. I asked how my baby was and all they doctor said was that she would pray. They did not expect the baby to live 24 hours and so they took a Polaroid picture of her for me and tolled my stretcher up and into NICU to see her. She looked fine to me, other than being hooked up to a ventilator and all the other monitors. I was told what happened when she was born. Apparently, Carlyne ruptured a blood vessel and that was all the blood. She lost 3/4 of her blood supply, thus her heart quit beating. She was born at 10:15. Neonatology was waiting for her and worked on her unto 10:30 to resuscitate her. This may sound morbid, but it makes me realize how close we were to losing her - the neonatologist told me that he was just going to call time of death when she took her first breath. She also received a blood transfusion upon birth and, in the event of seizure, phenobarbital was administered (and overdosed, we found out nine months later).

The next day, Carlyne was still living and holding her own. We were called into the neonatologist's office. He told us that, yes, Carlyne would live. But, she would be mentally and/or physically handicapped, to what degree, nobody knew. We were thrilled that she would live and devastated to learn the challenges she would face in her life. Carlyne was released from the hospital after two weeks (her due date). She would have been released a week earlier had it not been for the phenobarbital overdose. To me, she was a perfectly normal, happy baby, and that's the way I continued to think of her.

For the first year of Carlyne's life, we spent at least two days a week in doctor's offices. We went to pediatricians, neurologists, development doctors, physical therapy, you name it, Carlyne endured cat scans, KEG's blood work, etc. At one point, when she was three months old, and I was very happy with her progress, we had an appointment with the pediatric neurologist. At the end of the appointment, he said she appeared to be a normal, healthy three-month-old baby, but "don't get your hopes up - no child can go through what she did at birth and not be disabled in some way." I am happy to say that Carlyne had her last appointment with him at eighteen months and he said that he was very glad to eat his words and that she was the sunshine in his day. At thirteen months, when she started walking, Carlyne was released from physical and occupational therapy. At 2-1/2 years, my daughter knew her alphabet, could count to 10 and knew her first, middle and last names. Neonatology said they loved seeing her, but after that day, they never wanted to see her again. My daughter was finally given a clean bill of health.

Thinking back, if my doctor had looked further into the extra lobe, she may have had some indication as to the VP. Also, the first time I went into the hospital, had they tested the blood, they would have known that it was Carlyne bleeding, not me. And finally, if they had done a C-section that day, before any blood vessels had had a chance to rupture, she would have been born PERFECTLY HEALTHY and we could have all had a much happier and stress free 1997.

Bob, Ryan, Carlyne and I are very fortunate. Carlyne is alive and with us. This happy ending does not occur very often, if at all. We count our blessings and thank God every day for her. My goal through all of this is to make the medical community and people planning on families more aware of vasa previa and its complications. We don't want to scare mothers, but if VP is detected early in the pregnancy, it can be dealt with and chances are you can have a perfectly normal, healthy child with a planned C-section. One simple test can mean life or death to many children. 1:3000 is a pretty high chance. My goal is to make a color Doppler exam part of every prenatal program.

Debi & Carlyne

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My name is Marya and I live in the Tampa FL area. My little girl, Rebekah is a vasa previa (VP) survivor.

In May of 1999 I was beginning the last trimester of my pregnancy (my sixth, I have two older children and have had three miscarriages.) A prior ultrasound showed the placenta a little low, but nothing to be concerned about. That May, during one week I was not feeling well with cold symptoms. Rebekah's movements had slowed enough to really concern me, and I called the doctor. He said I should go to the hospital and let them put me on the monitor. That went fine; they said she was slow because I wasn't feeling well. Well while I was there, the Dr. ordered another ultrasound and that is when they found the vasa previa as well as a partial placenta previa.

They sent me home on modified bed rest for a few weeks. My Dr. grew increasingly concerned, I live 26 miles from the hospital and I was the first patient he had ever had with it, and he knew if something happened that they could not get me to the hospital in time. SO, in the middle of June, I was hospitalized for the remainder of the pregnancy I was told over and over again to tell someone of the slightest spotting and under no circumstances to allow anyone to do anything internally. The high-risk specialist said to perform an amnio at 36 weeks. If lung function was adequate, to take the baby then, if not, to wait another week and take her no matter what, situation was too dangerous to continue beyond that point.

It was a very difficult time for my family, especially for my 3 year old who didn't understand why I was in the hospital. Well, she was not ready, so they waited another week until July 6th and delivered her via c-section. C-section went fine, but she was having trouble breathing and was sent to NICU. She stayed there for two weeks. When I got her home she was 5.7 lbs. Now, at almost one year old she is 18 lbs and is a few months behind developmentally, sees an occupational therapist once a week to help her catch up. I have wondered if her small size and developmental problems were due to the VP (my second child was 10 lbs)

Marya Mesa & Rebekah

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When I was 17 weeks pregnant with my second baby, I went in for the routine ultrasound that every pregnant woman can get. During the exam, we would check baby's size, organ function, gestational age, sex, etc.

While my second pregnancy was much like my first, I was much more nervous during this one. But I had no logical reason to believe anything would be wrong. Aside from slight morning sickness and fatigue, I felt fine. My first pregnancy was normal, I was under 30, had never smoked, and was in good physical condition. There was nothing about my medical history that would put my baby or me at risk for anything.

I met my husband, Greg, at the office of Dr. Harris Finberg, a radiologist who specializes in obstetrics. During the exam, it took Dr. Finberg only took a few seconds to see a problem. He told me I had something called vasa previa. Despite immersing myself in pregnancy books, magazines, Web sites, etc., during both pregnancies, I couldn't recall ever seeing anything written about it.

As Dr. Finberg described it, vasa previa exists when a fetal blood vessel from the placenta or umbilical cord crosses the entrance to the birth canal, beneath the baby. He told me this meant I'd have a c-section and that my OB would discuss with me other implications and management strategies.

I returned home that evening and scoured my books and magazines for mention of vasa previa and found nothing. The closest thing I could find was a condition called placenta previa – a condition where the placenta itself completely or partially covers the entrance to the birth canal. I was relieved to read that placenta previa was very manageable and didn't pose much risk to the baby or the mother.

But when I spoke to my OBs about my diagnosis, I found out something very different. Since the blood vessel that crosses the entrance of the birth canal contains fetal blood, risk to the baby is very high. If the blood vessel breaks, the baby could lose all its blood in a matter of minutes – or less. The mortality rate associated with vasa previa is estimated to be as high as 95 percent.

They were going to treat me very carefully. I was immediately put on pelvic rest (no sex, no internal exams, etc.) and was told no lifting or intense activity. Since they wanted to keep a close eye on me, they prepared me for eventual hospitalization.

At about 24 weeks gestation, I began experiencing some uterine irritability. Knowing that contractions could cause dilation and ultimately a rupture, I called my doctors. They sent me to OB triage for monitoring and reminded me that I might not go home for a while.

My stay would last 74 days. While there, I was monitored daily, medicated to stop contractions and put on strict bed rest with only bathroom privileges. Being there also meant my baby had a better, but not guaranteed, chance of survival if a rupture occurred.

Being hospitalized was very challenging. Life as I knew it stopped. I was away from my home, my family, my friends, my pets and my job. I had no privacy, the food was between average and bad and my room needed a major redecorating. I felt like a caged circus animal.

But, whenever I felt badly about it, all I had to do was think of my options. I could either be at home, knowing that my baby could die at any moment, or I could not know about the vasa previa at all. I could go in to labor, bleed, and lose my baby.

I had it the best way I could have it. I reminded myself that my situation was temporary and that in five years; these months would only represent a blip in my life. And, for this small price, I could enjoy celebrating birthdays, holidays, and everyday with my child in our home – not at a gravesite.

Ten weeks later, after two rounds of steroid treatments and an amniocentesis, I delivered Claire Elizabeth at 34 weeks' gestation by c-section. She was small, but otherwise beautiful and perfectly healthy.

I still look back and am humbled by it all. We were so incredibly lucky to have had Dr. Finberg involved. I am convinced that if it weren't for him, my life would be dramatically different today.

With the help of the incredible women I have met through the Vasa Previa Foundation, we hope to increase awareness among women and the medical community. Women need to know about vasa previa and the medical community must look for it. As expressed by the Vasa previa Foundation's slogan, "It only takes a moment to diagnose life."

Susan Mulligan and Claire Elizabeth

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**In September 1996, we lost a perfectly healthy, full term baby boy to vasa previa (VP). Quite unexpectedly, as is most common. It wasn't diagnosed until he was delivered by emergency c-section after a sudden but brief bleeding episode at home. He only lived 38 hours - the most precious hours of our lives.**

Nathan was a complete surprise for our family. We were DONE having children. Having another one never dawned on us. It took months to get used to the idea of expanding the family again. By the time he arrived, we were really looking forward to it again. I had redecorated the nursery and made baby clothing and a new blanket. My oldest son learned to drive so he could help transport the others to ballet lessons and soccer practices.

Then I arrived at full term - my pregnancy had been completely uneventful. One morning I awoke very early. The baby was awake too. I relished in the thought of his upcoming arrival, shared a moment with him and we both fell back to sleep. An hour later I awoke and knew something was wrong. I reached down to find my hand covered with blood. I got up and ran to the bathroom. Sitting in the bathroom, I felt the baby turn and thought, "This may well be the last time I ever feel him move again."

My family called the doctor and I was taken to the ER right away. The bleeding had stopped almost as soon as it started. But there was a lot of it I was put on a fetal monitor that showed our child's heartbeat at 130 and "dipping". They got ready to do an ultrasound, but then his heart stopped altogether and we were rushed into surgery.

The next thing I remember was being told the baby was a boy, and was his name "Nathan"? I said, "Yes". I was still coming out of the anesthesia and thought, "It's a boy. A sweet boy. It's over, thank God, it's over!" I wasn't even able to open my eyes yet. Next, the surgeon came in with the placenta and explained what had happened and what vasa previa was. I still couldn't open my eyes or concentrate for much more than a moment at a time. It turned out that Nathan had had to be aggressively revived and was extremely ill. He was going to be transferred to intensive care at a local children's hospital. But he was here. He was alive. They got him out. I was scared, but sure he would be all right.

They brought him to me just before he was transferred. He was in an incubator type box, on a respirator and had tubes and wires all over. He reminded me of ET in that scene near the end of the movie. We had considered giving him the middle name of "Elliot". Now I was sure it should be "Elliot". I was sooo happy to see him, but the hospital personnel were somber and serious. They handed me some Polaroids they had taken before he left the operating room. He'd already had two units of blood.

After that visit with my new son, I was moved to a room in the maternity wing. Phone calls started coming in. My sister-in-law delivered her baby THE VERY SAME MORNING! It was excruciating receiving phone calls from excited family members who were initially unaware of Nathan's demise. It was along day and news from Cardinal Glennon wasn't good. Two EEGs showed no brain wave patterns. My baby couldn't maintain a proper pH, blood pressure or body temperature.

Against medical advice, I got out of bed the very next morning so I could be with my son. Suddenly I felt extremely guilty about abandoning him during his first 24 hours. If he was going to do well he needed his mother, now more than ever. I asked to be transferred to his hospital. They would not allow it. I told them I was going anyway. They gave me a "pass" and I left. My poor child! The drugs were not helping much to stabilize him and they couldn't give him much more

because his kidneys were not functioning. Specialists determined that his kidney problems would probably improve on their own if his overall condition improved. I left with a heavy heart. By the time I was settled back in my own hospital, Nathan's doctors were calling. He was getting worse and they needed to discuss things like "heroic measures". Oh, God! I was back at Cardinal Glennon Childrens' Hospital within 30 minutes. My other children had just been there to see their brother. Word was sent to intercept them and send them back up to the ICU. Nathan's condition was desperate. His kidneys were now bleeding which meant he would never regain use of them. Every organ in his body was shutting down. We simply could not let him die alone in that crib. His father held him for a few minutes then Nathan was placed in my arms and removed from life support. He squeezed my finger when they pulled the breathing tube out of his throat. We were moved to a private sitting room in the ICU where Nathan's brothers and sister took turns holding him. He met his grandparents and some of his aunts. We loved him. And then we let him go. At 10:50 pm he stopped breathing and was placed back into my arms where he took one last breath and passed quietly from this world.

Cindy Paris and Nathan Elliot

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I am 39 years old and have a beautiful daughter, Marie Claire who is 6 1/2 years old. I had been promising her a baby sibling for years and had had a miscarriage and D&C in April 2000 when at 10 weeks no heartbeat was found. In December 2000, I discovered I was pregnant again. I was thrilled. The pregnancy went pretty well, although I experienced severe vomiting during the first five months.

From the beginning I had voiced concerns to my Dr. because my cousin and one of my best friends had lost their babies in 2000, days before their due date, one due to an apparent cord strangulation and the other still does not know how. Because of this, I had asked the Dr. for a color Doppler ultrasound the last four weeks of pregnancy to check for cord positioning and although he initially said yes, at around the 36th week he said no to the ultrasounds because the color Doppler was too expensive and insurance would not cover. He reassured me I was fine anyway and not to worry. He said that even if I did a weekly ultrasound, the cord could strangulate the baby at any time (not too reassuring).

After my amnio in late March, the doctor told me I had a marginal placenta. I had several ultrasounds and in June the placenta showed to be low lying. In ultrasound on 7/13, the placenta had risen to normal.

At the beginning of week 38, I was diagnosed with high blood pressure. As soon as I learned about the condition I began to practically beg my Dr. to induce me or do a c-section, but he refused arguing that since the cervix was high and closed and the baby was not yet in my pelvis, induction would lead to c-section, which was too risky. No matter how much I begged, it all fell on deaf ears. I was sent home and ordered to lie on my left side for a couple days. I stayed pretty much on bed rest since then.

I was admitted to the hospital two days before my due date on 8/24/2001 at 3 a.m. after passing two large clots of blood at home and then bleeding a LOT more than normal, approximately 300 cc's of blood (although Dr. and nurses asserted this was normal bloody show). The blood was very liquid, not clotty and I kept asking at the hospital how come I had bled so much but the doctor never ordered testing of the blood. Instead he ordered a regular ultrasound (not color Doppler), which indicated a score of 8/8 and after 8 hours of monitoring I was discharged from the hospital even though I begged the Dr. to "get my baby out" and to keep me in the hospital. The doctor told me the hospital was full, the nurses were busy and they did not have time for an elective procedure. I went home distraught.

Then the unthinkable happened 2 days later. I was in bed at 11:30 p.m. and felt my baby kick. I said good night to her. And then a second later, I felt a warm liquid. It was not my water; it was blood, lots of liquid red blood. As I sat on the toilet bleeding profusely, I called the Dr's service and he called back 5 minutes later. Although I specifically yelled that I was hemorrhaging profusely, he calmly said, "OK, we are going to deliver this baby, go to the Hospital." He told me to drive to a hospital that is 8 miles away instead of to the nearest hospital that is 1/2 mile away and he has privileges there too. Upon arrival there, nurses checked for fetal heartbeat and none was found. It was only then that they notified the Dr. and he arrived 10 minutes later. Ultrasound found no heartbeat, 40 minutes had passed since my call and my Sophie Isabelle was declared dead at 12:11 a.m. on 8/27/01. My worst nightmare had come true. My cervix was still high and closed. We proceeded to induce and I delivered at 6:30 that morning. Sophie Isabelle was a beautiful 6 lb 11 oz baby.

The blood on Friday the 24th was fetal blood, not maternal blood, due to a small membrane rupture. This was a huge warning that was ignored. If the doctor had had the blood tested with a simple APT or Ogita test, he would have realized this was no "normal bloody show". Two days later, on Sophie's due date, two days after our last warning, she lost her life when my membranes ruptured and she exsanguinated due to vasa previa.

I am now working with the International Vasa Previa Foundation to increase awareness of this devastatingly fatal condition amongst the medical community and pregnant women. 95% of vasa previa diagnosis made antepartum result in the successful birth of healthy babies when correctly managed by the OB, but up to 95% of vasa previa cases that are undiagnosed result in the death of these otherwise healthy babies. A simple transvaginal ultrasound with color Doppler as early as the 16th week of pregnancy can diagnose vasa previa and prevent an almost certain fatal outcome. It only takes a moment to diagnose life.....

Victoria Goldstein and Sophie Isabelle

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Last year, in June, Robert and I decided to let nature rule. We have always wanted children and we thought that the time was right now. We both felt like we were ready, and able to give our child a bright future, surrounded with our love. Everything went great, we had a wonderful pregnancy. ! I did not get morning sickness and the check-ups at the midwife were terrific (blood pressure, blood- and urine samples, heartbeat of the baby).

Because we were not certain of the date the baby was due, we had an ultrasound in December. We were thrilled when we found out that I was one more month pregnant than we thought. Everybody said I looked radiant from happiness and I felt great! Through the whole pregnancy I had no complaints at all. Of course I slept less comfortable at the end and walked less flexible but that is normal.

When I got my pregnancy leave, four weeks before the due date I had enough energy left to paint the house (inside) and do a lot of little jobs around the house, which had to be done before the baby came. I traveled throughout our country to visit my friends and sister-in-law who had just delivered a baby of their own. On Wednesday, May 23, I drove all the way to the south of the Netherlands (2,5-hour drive) to visit my parents. I went shopping with my mum to buy the last baby stuff (clothes, a photo album), and we couldn't stop talking about the baby. The next day we would drive back to Kwintsheul (near The Hague) and she would help me clean our house and bring the baby cradle, which my mum and my dad had made themselves. The whole family was very much involved in my pregnancy. They were actually a little bit pregnant themselves. It would be the first grandchild for my parents and the second one for Robert's father, who had just welcomed his first grandchild 4 weeks ago. We had a beautiful picture in our heads of how our child would grow up together with little Julian, the son of Robert's brother, and how they would play together.

But that night, from Wednesday to Thursday, my water broke, at my parents' house. I went to the bathroom at 3.30 in the morning and noticed that I could not control my urine, so I thought. Back in bed I felt fluid flowing down my legs and then I realised that it could be amniotic fluid. My mother and I couldn't sleep anymore and at 6.00 we got up and drove back to Kwintsheul. I phoned Robert out of bed. We were so excited! It had started; we would soon be mum and dad.

The midwife came by when we were back in Kwintsheul and she confirmed it to be amniotic fluid. The fluid was clear as water with little dark hair in it: baby hair of our long expected child! If the contractions would not start the next morning I would have to go to the hospital where they would artificially provoke the contractions. This because there would be a big chance of infection if we didn't do so. That day we were in a party mood. We knew for sure that we would become mum and dad that particular day or the day after. We asked my mum if she would like to be present at the delivery and she was thrilled. Robert went to work that day to finish the current things and to tell everyone the good news. We agreed that when the contractions started I would immediately call him and he would come straight home.

I went to the greenery to buy a fresh pineapple, which I ate completely, because there appears to be something in the heart of the pineapple that starts the contractions, at least that is what I read. But the contractions did not come that day, or the night after. Too bad, because we would have loved to deliver our baby at home. But going to the hospital was extra safe, we would have nothing to worry about. There would be a whole team of professionals and thus nothing could go wrong.

On Friday morning, May 26, we arrived at the hospital at 8.30. I had to lie down in the middle of three beds in a row and got belly ties attached to measure the contractions and the heart of the baby. The doctor came to introduce herself. It was a young enthusiastic doctor (named Annemarie) who reassured us: getting into labour in a hospital is great fun!

The heartbeat of our baby was an example of how it should be, and thus it was perfect! When the doctor touched me inside, I appeared to have an opening of 3 cm, which was great. This meant that they could start the injection with oxytocine through a tube immediately. Before going into the delivery room I had to go to the bathroom and I noticed a little bit of blood upon the toilet paper. But they told me that it was normal after the touching.

Then Annemarie came by to insert a pressure meter to measure the intensity of the contractions, and an electrode that they would screw on the babies head to measure the heartbeat of the baby. But when she inserted the pressure meter, an enormous amount of blood came out of me. I was terrified and tears started to roll down my face when I saw the look on Annemarie's face. 'Milani, now!' I heard her shouting. After a telephone call from the assistant, doctor Milani came in, the gynaecologist. Annemarie still had her arm inside of me; she didn't dare to pull it out. 'Solution?' she asked. 'No, the blood is too thick for a solution', doctor Milani replied. When Annemarie pulled her arm out of me a second stream of blood came out. The gynaecologist put the electrode on our baby's head anyhow and we saw the heartbeat decrease. For one moment it looked like it was stabilising but then the heartbeat rapidly decreased.

I was taken to the operation theatre in a rush were they delivered Julia with a C-section. This was around 15 minutes after the blood came out for the first time. Our baby came out of my uterus at 10.01 without a heartbeat. The paediatrician took over and started to clear her lungs and apply heart massage. In the meantime they tried to bring new blood into her blood-circulation but they failed. After 17 minutes of reanimation they gave up on her. Robert was there, during the reanimation and for ten long minutes he still had hope. The doctors were working on her, it should be all right. He held our Julia in his arms while I was waking up from the anaesthesia. I saw people in green coats all over me were driving me across the corridor to the delivery room. They all looked very sad. 'How is my baby?', I asked, but no one answered. I asked it again and again. 'The doctor will be here any minute', one of them replied. And then I knew. I started crying and suddenly I heard Robert crying heartbreaking. 'No!!!', I shouted and Robert put the baby in my arms. 'It's a girl,' I heard somebody say. She was so beautiful! This wonderful little creature, our Julia. Why? How is this possible?

Later it appeared to be diagnosed with Vasa Previa and velamentous insertion of the umbilical cord. This was stated during the operation. While inserting the pressure meter they probably have ruptured a vessel, which belonged to Julia and made all the blood in her body flow away. A little baby has only 300 ml of blood in contradiction with an adult who has 5 litres. She was perfectly healthy, a beautiful girl of 3625 grams (which is a little more than 7 pounds) and 50 cm. She had everything present to be able to cope with the world. But it was not meant to be.

Our whole world collapsed, we had been looking forward to this baby girl so much, she was so welcome... Suddenly your hands are empty and my belly too. And this while everywhere around us perfectly healthy babies are being born. Why us, why our baby, she still had everything going for. Why did they have to use that stupid pressure meter while the ties around my belly also worked all right? Why didn't they do a check-up before after which they would have performed a C-section immediately. All questions without an answer.

She will always be our first child, our Julia and we are her proud parents. We have beautiful pictures of her that we love to show to everyone. But life at home, after the hustle and stir of the funeral, is empty and meaningless. Everything brings up memories of her and the life we could have had with her, the life we desired so much. The days are filled with tears, consternation and search for distraction. It will still take a long time for us to deal with this enormous loss. Life goes on around while for us the world seems to stand still, we do realise that. And we also know that the tough edges of our sorrow will wear off. We also know that life will have its new beautiful moments where we can get our strength from, although it is hard to imagine that right now. It just takes time.

We want to do something with all our feelings of unbelief, anger and inability we have right now. We want to prevent other people of losing their babies the same way as we did. Internet taught me that Vasa Previa is a symptom that appears in 1:3000 pregnancies. I would say that is a whole lot! The mortality rate is 50-90%. With a Doppler Ultrasound it can be made visible in advance and a C-section can be made.

Besides this we are furious about the insertion of the pressure meter that seems to have ruptured the vessel of our little girl. They seem to use two kinds of pressure meters in the hospital we went to. One is very thin and flexible while the other one, the one they used, was very stiff, surly and big. In the delivery room where I was brought to they used instruments that could only be combined with the stiff pressure meter. The doctor that inserted the meter (Annemarie) told us afterwards that she would never use that kind of meter again. Too late for us though.

From others we heard that the hospital of their choice did not use any inserting material at all. They use the belly ties through all the deliveries. Having used those, Julia would probably still be alive. Especially because 50% of the babies that die because of Vasa Previa, most of all die during the rupture of the membranes and they were already broken in our case. Nature did his job right, it should have gone well.

We recently found out about an academic thesis named: The policy of premature broken membranes à term by P. Ottervanger. She contradicts the words of the midwife and the hospital; in fact she says that it is preferable to wait for the contractions for 48-72 hours and that the chances of infections are to be neglected. When nature would have gone its course, there would have been a chance that Julia would have lived now. Besides this Ottervanger wrote about Prostaglandin as the preferable way to provoke the contractions, above oxytocine which involved inserting the pressure meter. Why didn't they use that?

We feel that the medical science has failed. We had 3 chances of bringing our baby healthy to the world. By waiting 48-72 hours before artificially starting the labour process, letting them investigate me through ultrasounds before inserting dangerous instruments, by using a belly belt instead of a pressure meter. We do realise that it will not bring our angel back but we cannot put it aside us. Somewhat later, Robert thinks he remembers that the obstetrician -who has performed the Ultrasound in the beginning of our pregnancy- told us that the umbilical cord was not in the middle of the placenta, but that seemed to be no problem according to her. They should have investigated us further then already.

We've had two appointments with the gynecologists. They feel that they have to do something with this case and told us they are going to organise a congress about Vasa Previa in Holland. They want to share experiences, discuss how to prevent situations like ours and how to act when the blood loss does occur.

Marlou van Dijck and Julia Elisabeth