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Terri Schiavo, Inc.

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TERRI SCHIAVO, INC.

A Performance Piece by
Jyl Lynn Felman

The problem with Terri, Edith Jeanne, and Susan. None of them can speak for themselves. Those girls can't speak, can't say a fucking word, can't even say *shut up* whenever they fucking feel like it. But I can. I do. I will.

I am. Saying fucking shut up and listen while I explain the entire situation which has gotten very out of hand besides tearing this whole country apart. It's emotional, that's all. Very emotional for all of us who got ourselves and everybody else directly involved.

Everybody has to have their say but the girls themselves. Who can't. Say a word. Or spell. Out loud. The letters. It's not about getting a word in edgewise. It's about getting a word out. Period. O-U-T. Out. Out. Out. And they can't. The girls. Speak up or out. For themselves. Exclamation point!

Exclamation point!

The girls can't say a fucking word. Can't even whisper. Their mouths don't open. And if they did. I can hear them screaming. One giant comatose sisterhood all together.

And the word "NO"—that nobody wants to hear—is a small word. And doesn't take up a lot of space even though the problem itself just keeps taking up more and more space. "No" is small,

little, tiny, hardly noticeable at all. The word the girls with their mouths closed shut tight forever would say, actually scream if they could.

The word that nobody wants to hear that I'm forcing myself to say. The word is "NO." Plain and simple. "No." You can fill in the rest...

I'm filling in, that is I'm going to speak for them because I know that's what they'd want if they could. Speak, that is. I just know it. If they could speak about not being able to speak they'd choose me. To speak. For them. Even though it's ridiculous. Because nobody can ever speak for anybody else. But I'm going to try to. Speak. For them. Because I want to.

Most important I can be objective because I'm a lesbian, not married, ambivalent about school vouchers, pro abortion, never been Catholic, not an immediate family member, or a Christian fundamentally elected official. Nor will I ever run for public office or be appointed to the Supreme Court of the United States. Plus I'm way too old to rent out my womb on a case by case basis. They call it surrogacy.

I'm completely devastated that my eggs are too old for donation because where does that leave me, as far as my worth as a patriotic woman goes? In these times of greater insurgency. I mean what more can a woman do for her country but sell fresh eggs, give birth or die a slow agonizing death? And if a woman has to die to give birth does that make her worth more. Worth more than what? Am I even allowed to say what I really think... No. And it's not only me. The entire country is suffering from a serious case of locked jaw whether they know it or not.

This is where it gets confusing—I mean, if I (could) give birth to someone else's child doesn't that make me the real life birth mother and the other woman the surrogate stand in? For me. Like I am standing in right this minute for Terri, Edith Jeanne, and Susan. Which makes me their ersatz replacement substitute surrogate mouthpiece. Doesn't it?

Everyone needs a substitute secondary—ersatz—mouthpiece waiting in the heroic wings of the hospital the minute the ability to speak for ourselves is lost due to medical emergency or preventing domestic terrorism. Currently every woman's body is at serious risk. Whether she knows it or not.

Just the other day my brain slipped and said "unborn child" when I told it to say "fetus." And then I didn't know what to say. I was afraid the word "fetus" got lost for good and that my brain was actually dead and that I couldn't remember the difference any more between a fetus and an unborn child.

I don't ever again want to look up and see my brain going dead right in front of my hazel brown eyes. Or a pink fetus turn into a white unborn child.

The words just merged into each other like one big traffic jam on Interstate 91 going South—BAM — BAM—Rear ended. Swoosh... side swiped...and then crash broken glass...fetus...unborn child...the child is an unborn fetus... the unborn is a child fetus...the fetus is a child un-

born. In the traffic accident, right inside my head, they merged so close together I couldn't tell them apart.

That's when I knew my brain cells were rapidly breaking down—shrinking—when I confused the three most important words in the United States language today.

But a fetus and an unborn child are not identical twins and never have been. They're not even fraternal. It matters if you want to stay sane to keep your definitions straight and apart. No matter how very much like two homonyms stuck together the words themselves seem to be.

Just *unborn that fetus* is what I say. Now and forever more.

But I'm jumping ahead of the story.

First, the who's who of WHO is everybody. I'm sure you're familiar with the life saga of Terri. Terri Schiavo. Who was married to Michael Schiavo until the day she died. That's right, Terri's here on a temporary visa to set the record straight. That is, to have me do it for her. Set her record. Straight. She's convinced her parents will listen to me because I'm the only one in the middle of this entire mess who makes any sense. I'm the only one taking a serious look at the meaning of life.

I'm a Jewess which is a female Jew. And, for the official record which always makes the Vatican furious, we Jews don't believe in life after death. One chance is all you get. So in terms of "life after death" if anything happens to my Jewish brain it's not like we're going to meet up again later on. Me and my brain. It's now or never as far as the brain and its healthy tissue are concerned.

But Terri's brain is another story. One that everybody who is anybody is trying to tell.

And how would you feel about that? About watching someone else decide how to end your life story because you can't decide for yourself anymore. We're talking about life and death and NOT your spouse or best friend placing your order at McDonalds because you've stepped into the Ladies Room to wash your hands and because they think they know what you want to eat.

That's just it. We think we know what someone else wants for dinner but when it comes time to place the order, make that final grand decision, we actually have no idea what-so-ever. Only no one wants to admit it.



Terri's parents have to listen to me because I have no monetary stake in the ultimate outcome. And I can't sell the story to anyone. It's not my story although one day or any minute it could be. Because I could collapse and so could you and together we might never wake up. And then someone else would have to decide what to do. With us. For the rest of our entire lives.

What I want to know is how can someone tell someone else's story? I mean, how would you know what to say if it wasn't your story. In the first place, you can't ever know someone else's story. You can't ever know someone else's story or what they want for dinner as intimately as you know your own taste buds. Which most of us don't even know very well. Our own true story vs. the story we tell whenever we're asked to tell our story. Besides it changes every time. The taste of the story on your tongue is never the same twice.

Anyway, Ms. Schiavo is the one with the feeding tube inserted into her abdomen for fifteen years. No. It didn't hurt. She couldn't feel a thing. Even when the doctors finally took it out. I know for a fact that she didn't feel a thing because people who are brain dead don't feel a thing no matter how bad we want them to.

When we're feeling the thing we want them to feel. We tell all the newspaper reporters that there's feeling there and has been all along. And Terri's parents were definitely feeling what Terri could not. A lot of emotional pain. But over the years, it all got so mixed up. In their minds. Who actually was in pain and who was not. In pain.

Physical or emotional. It got all mixed up.

(I'd like to move on with the story. Get all the facts out in front before anything is decided permanently.)

Edith Jeanne Felman you're probably less aware of. She's from Ohio. Yes, Dayton. EJ had to sit very still in a wheelchair for over seven years and by the end she couldn't say a word. About what she wanted or didn't. Want. To say. She and Ms. Schiavo have that experience in common—not being able to speak for themselves.

Only EJ who happens to be my mother didn't have a feeding tube. She had her husband, my father Marvin who acted just like a feeding tube only he was alive and much better than a feeding tube which can get all clogged up. My mother was lucky. She never went hungry and there weren't any huge legal battles.

The other woman involved in this highly dramatic real life performance—and it is a performance *summa cum laude* simply over the top—is less well known than Ms. Schiavo. But she resurfaced the same time Terri's autopsy surfaced. It was as if it was all planned ahead of time. First Edith Jeanne, then Terri, and now Susan.

The weirdest part of the whole scenario is that Susan's last name is Torres so the letters are reversed. TS for Terri Schiavo and ST for Susan Torres. Of course it's significant; there's a metaphor inside those letters just waiting to pop out like a ripe buckeye. Only the buckeye isn't ready

to pop—not yet anyway. Not until I have my full say.

A metaphor. What's a metaphor? Something that stands in for something else. Only there are no metaphors for Terri, Edith Jeanne, or Susan. Because metaphors create meaning and good ones are magical and give deep insight into the human condition. But Terri had no sight and the Parkinson's has no deep meaning other than the fact that it paralyzes the whole entire body eventually over a long period of time while keeping the damn brain alive. And I mean alive. Like Edith Jeanne's brain was alive even though she couldn't scratch her left elbow with her right hand.

Or yawn when she was exhausted. Which she was from sitting in the chair all day. Like Terri lying in that hospital bed for fifteen years. Those girls were tired. Tired of all of us fighting over their almost dead bodies. Only they couldn't say a word.

Like all three of those girls are driving down three different connecting ramps to the same long highway leading exactly nowhere. And the deep meaning will be revealed to all of us shortly.

Across Edith Jeanne's—my mother's—face Terri's parents could if they wanted, see the flicker of recognition they were always talking about crossing Terri's face. Beginning in her eyes.

My mother's eyes flickered in recognition even if no one was present to witness the flicking motion. The Parkinson's didn't get into her eyes.

Exactly the opposite of Terri's condition —Edith Jeanne was in reverse trying to go forward. But she couldn't move the wheelchair or press the “go” button by herself. No matter how well that brain of hers was working. Maybe if the doctors had taken my mother's brain and implanted it into Terri's brain one of those women would be walking and talking fully alive today.

About Susan Torres. She's the twenty-six year old pregnant in a melanoma cancer induced coma whose brain—just like Terri's—has stopped functioning like a brain functions and is instead shrinking this very minute as we speak you and I. Brain dead they call it. Smaller and smaller. Shrinking. Until it disappears right inside itself.

But Ms. Torres is not being allowed to die a natural death. On account of the fact that there's a little bit of life growing inside of her. And her husband Jason swears that his wife would want that life to have every chance it could to survive even if the mother herself is brain dead and can't ask for a cup of black coffee for herself. Or even sit up and drink it.

Edith Jeanne wasn't brain dead when she stopped talking one day she just could hardly open her mouth to say a single word like “hello” to Marvin her husband the feeding tube. Her vocal chords stopped vocalizing and she never said a word after that day. People with Parkinson's often lose the ability to speak but their brains don't die; they just curl up and cry. Long silent tears. For many hours. And hours. And minutes too.

You can see it in the eyes. In EJ's eyes which were different from those of Ms. Schiavo who was found to be blind at the moment her eyes were searched at the autopsy. I still can't believe that no one, not a single one of those doctors, especially that medical person William Frist Billy Boy who calls himself Senator, couldn't tell she was blind. When he watched it all on Reality TV—Terri's Video, that is. It's a new kind of diagnosis—live from the screen, no matter how far away the doctor is. He knows what he sees.

Even her parents, the Schindlers pretended their daughter could see. At the moment, there's been no mention of what Susan Torres sees or doesn't see. While the melanoma moves fast. Down into the rest of her body, heading straight for the placenta.

Moves fast, the doctors say, this kind of melanoma could cause brain damage once it invades the placenta.

If the unborn fetus is born brain damaged from a brain dead woman who can't speak for herself but is kept artificially alive on a ventilator, whose fault is it, anyway? The mother's or the doctors? The husband or the parents? And who is the DA supposed to bring up on criminal charges of woeful neglect of a minor under the age of sixteen? And who can the fetus sue for the infliction of fetal entrapment?

The fetus is already brain damaged as far as I'm concerned. Not a chance in a lifetime for the damage to be undone or surgically altered in the near future because the kind of brain damage going on inside Susan Torres' womb is one-of-a-kind that kind only a mother understands. For sure.

It's very emotional; that fetus feels everything the mother can't. Don't kid yourself about whether or not there's going to be any real live brain damage. It's way too late for that. For the mother and the child. All there is, is damage from the damn pain. Of everybody speaking for the mother who can't speak. But what if she could. What would Susan say now?

As it is she can't say hello or even pat her growing tummy. Right this very minute the melanoma is spreading to her lungs. And Susan can't say a word. But the doctors aren't concerned because it's nowhere near the uterus. Yet.

Right after her collapse Susan's husband Jason quit his job and moved into the hospital room to be with his wife even though he's basically acknowledged that she's not really still actually actively alive all that much.

But he wants to be with Susan as long as she is alive, well, sort of alive. In this case unlike the Schiavo situation, the brain dead daughter's parents agree with the husband's decision to let the doctors keep his wife artificially alive. So clear as a bright sunny day that makes Jason Torres the good husband and Michael Schiavo the bad one.

After a man like Jason Torres has his say there is no way a Michael Schiavo type can win in the American eyes of a furious public. In fact, Michael Schiavo—according to Tom DeLay—has

long been an eye sore to the Nation according to the White House. How dare he try to speak for his brain dead wife who lost one hundred pounds starving herself to fit into the wedding gown of her dreams.

But isn't that exactly what Jason Torres is doing. Speaking for his wife Susan who was hoping for a girl before she went into the coma.

Even the doctors go back and forth about Susan. Whether or not under the Hippocratic Oath what they're doing is truly life saving. Or just another very expensive not covered completely by health insurance medical experiment. Mostly this country is against human medical experiments. Using the human corpus to find answers to difficult pathologies is extremely controversial.

Remember Josef Mengele, he was the infamous and notorious doctor during Hitler's time who performed outrageous surgical procedures creating one deformity after another inside the wombs of silent women? No one ever heard the women cry out...

When is a woman silent because she wants to. Be silent. Or when is there simply nothing left for her to say because the world around her has ceased to treat her like the full human being she is. And instead turns her into a human incubator that's later discarded?

As it is, when the next five weeks are over, in mid July 2005, the plan is to cut Susan's stomach wide open—caesarean style—and remove the baby with the umbilical cord intact. Once the cord connecting mother to child is cut snip-snip then it really is over. For good. As far as Susan Torres is concerned. So goodbye Susan.

But I'm not sure the Nation is ready for that kind of ending. Just throwing the body out as soon as the job is done. What I mean is after the baby's born and they don't need Susan anymore. Who's to say the parents won't change their minds. And want to keep the mother alive to see if she can breast feed her new baby? And then they'll let her go naturally. When there's no more milk.

Jason says after the birth he's prepared to let his wife go even though it will be hard. But he'll have the baby to take home. Not right away of course. That baby will have to be transferred immediately. Susan was hoping for a girl. It will be several more months before the child can be safely removed from all nonhuman life supporting systems.

And the parents agree, but what if they didn't. Agree to keep their daughter alive week after week while the melanoma spreads and the bouts of pneumonia and fevers and bed sores have to be attended to. For the sake of the gestation period which is at a minimum twenty-five weeks. Who's in pain now, is what I want to know? I am. Just talking about it. Hurts like hell. Because I am a daughter. And I can feel everything.

Jason finally agreed to talk to the media people because he knew there wasn't enough money to keep his wife and unborn fetus alive for over six months which costs seven thousand five hun-

dred dollars a day. And who has that kind of money? So young Mr. Torres went on national TV to ask for help from the good people of America who came through pledging thousands of dollars on the Internet instantly. Another miracle.

A question I still want answered is what would Terri in her vegetative state see if she saw. Vegetation. Looking down at her toes maybe she'd see baby red radishes. Wiggling *hello*. Five on the left. Five on the right. Wiggling *how are you* since she can't say a thing for herself. I can see those toes. And the radishes are a great shade of red. She wouldn't need any toenail polish; they'd be bright enough already. Those baby red radishes. I mean toes. Terri's toes. For fifteen years she couldn't wiggle those toes. Of course they turned vegetative.

Isn't that what they keep saying? The parents, that there's a chance. One day their daughter might be able to wiggle her toes. She's lying there just waiting to wake up from her inactive state. What the hell is a vegetative state? Terri's legs might very well resemble corn stalks with her brain dead head peaking out at the top—one big ear of sweet Ohio corn. Pearl white. Nodding, swaying right there in the wind. Not really moving but not dead either. That's a vegetative state. The corn is persistently waiting until it's the right color for picking. Or shrinking if there isn't enough rain in the season the corn dries up and turns vegetative. And nothing anybody does can bring that sweet corn back to life.

Dead corn is fed to barn animals while the left-over stalks are used for Halloween. Or scarecrows presiding over fields of orange pumpkins in early fall. But the real question is whether corn is really a vegetable or is it a fruit? Like the tomato. And can a piece of fresh fruit end up in a persistent vegetative state like Terri?

How long can it last like that anyway. And where on earth does that leave Edith Jeanne. And Susan Torres and the state of nonexistence that she's currently residing in. Her husband Jason calls her a husk—a carrying case. That's where I got the idea for the corn metaphor. We're all just ears of corn hanging onto our stalks for dear life.

And after the doctors finish husking Susan Torres—metaphorically speaking—they're going to throw her out like an ear of dead good for nothing corn.

Where are Terri Schiavo's parents when you need them? Now that Terri's dead all their energy should be directed at keeping Susan Torres artificially alive. Because they fought so hard for Terri, why not fight for Susan Torre's right to live? Especially when they don't believe in throwing anything out until it's truly time. And Randall Terry Mr. Operation Rescue is being awfully quiet about the Susan Torres affair.

So, it's true—after all—in America the baby is always worth more than the mother. Which means biology is actually destiny and a woman is only as good as her womb is in working order. While Terri Schiavo becomes the desperate fetus fighting for life as the Schindlers battle Michael in a hard cruel world full of nonbelievers because he didn't want his wife to suffer anymore.

But Terri wasn't his wife, she was first their daughter who before that was a baby girl in her mother's arms and before that was a fetus tucked warm and safe inside her mother's sacred womb and the Schindlers wanted to keep her that way. Warm, safe. Totally dependent on her mother to breathe. When does a daughter ever get to be a woman? And breathe on her own. Without her mother's breath. And speak for herself even when she can no longer speak she is speaking to us.

Nobody in the news suggested that they keep the Pope artificially alive so the people could continue to pray at his feet. They could have propped him up at the window where he always stood and waved down at the crowd. He was a very important man—the Pope—and spoke over seven languages. But when it was His time, it was His time. The Vatican just let the people cry while a new pope was picked.

After the Pope died, I wondered if he was mad that nobody hooked him up to a ventilator. But the word from the Vatican was that he was ready. To go. Even though the Pope didn't write anything down about what directions the doctors should or shouldn't take. Like Terri and Susan, He didn't say a single word. He didn't have to.



They let the Pope go without interfering or setting up any miracles of medical science to keep him artificially alive. Just because the people weren't ready to say good-bye didn't mean they had to keep that man alive. Whose life was it anyway? The people or the Pope's.

I'm glad they let him go instead of pushing him back inside his mother's womb. The Pope died with dignity and that's the way I want to go.

No. It doesn't matter that he was a public personality who was very beloved and had a huge following. Terri Schiavo was very beloved and had a huge following and they kept her ventilating for fifteen years until the courts just put their feet down. Terri was a woman and the Pope was a man. Don't you get it? Nobody speaks for the Pope. Even if He can't speak for himself. They wouldn't dare. They just said *goodbye*.

But the Schindlers weren't ready to say goodbye. To Terri. A mother is supposed to die before her children die. There was no way that mother could kiss that daughter goodbye and feel okay about it. Not after watching her starve herself all those years, just to slip into that gorgeous wedding gown and glide all the way down the aisle.

For all those years, the mother watched the daughter starve herself and didn't do a thing. So she can't no matter what let it happen again—even if her daughter doesn't want to eat any more. Terri's mother can't let go. How could she? Mothers can't let go even when they do let go. It's simply not possible.

For Edith Jeanne it's too late. Except to crawl inside her brain and imagine what it is she's whispering to herself about. All those years she was in that wheelchair I always wondered what my mother wanted—to be alive or not. We never talked about it. The quality of her life. It's come to me recently that Edith Jeanne wasn't happy about the situation. About being kept alive even though she had the best feeding tube love could buy.

It was hard near the end to even look at her, my own mother stuck in a wheelchair because she couldn't move on her own. Not a single limb by herself. Limb to limb she couldn't move unless someone did it for her. She had to be dressed and undressed; taken to the bathroom and wiped clean, including brushing her teeth. There was nothing Edith Jeanne could do. For herself. The end was really the end. Except it went on and on. For years she couldn't talk. Anybody, the nurse, my father Marvin, me the daughter could have put a pillow over her face and held it down.

Long enough for my mother to stop breathing. She wouldn't have put up a struggle. She couldn't move. But no one reached for a soft feather pillow.

I wanted to ask him why? Why he kept her alive; kept shoveling food into her mouth all those years when she couldn't even smile back at him, her loving husband. And he loved my mother, his wife. I cannot believe she was happy in her condition. With the Parkinson's, she couldn't talk. Express the slightest feeling. My mother's face was blank. My mother wasn't in her face. I don't know where she was. I couldn't find her once she sat down for good in that wheelchair.

And even when I took her to the bathroom I didn't mind so much because we even laughed about it, a few times, in the beginning. But then, one day, she couldn't bring a fork wrapped in spaghetti up to her mouth. And then, one day, she couldn't talk because her mouth could barely open. She stopped saying "hello" when I came to visit. And just stared. At me.

I always wanted to ask Marvin my father her primary caretaker if it was worth it. What did he get out of keeping her alive all those years. There was no outside ventilator hooked up keeping my mother alive. She didn't need one. Marvin was her ventilator, and he kept her alive and didn't put her away and didn't put a pillow in her face. And hold it there. The pillow. Long enough. It was a long time to see your wife sitting in a chair and not be able to get dressed up and go out for dinner or bring home Chinese. Or have her ask about your day and *what do you want for dessert*. Because she made brownies with walnuts. And chocolate bits.

It was too much for me. Too much. Having Edith Jeanne be alive and not be alive all at the same time. Even though I didn't live there and only came for visits. What was accomplished by keeping my mother alive when she couldn't walk or talk. Eat by herself. Take a bath. Put on her lipstick.

Waiting for my mother and Terri Schiavo to be able to die these last fifteen years, and now with Susan Torres, I can't take it any more. Can you? I'm obsessed with the whole question. Like, now that Terri's dead, where are the Schindlers? Why aren't they speaking out for the cause? For life itself. All life not just their daughter Terri's life.

Because that's what it comes down to, doesn't it. Life. Itself. Why must we fight for life at all costs. Can you explain this to me. I'm not kidding. If I was home alone with my mother I would have asked her if this is what she wanted?

I'd say Edith Jeanne, Mom, just blink your eyes. Do you or don't you want to stay in that chair for the rest of your life. And I just know what she'd say, and I think my father knew too, like Terri's parents knew only didn't really want to know. Why? Why do we keep people alive who we know deep down inside want to let go—like the Pope, who didn't say a word but was allowed to go. But we can't all be the Pope.

Can a daughter even ask. Such questions? Because I've made my decision and I am asking. These questions. About my mother's life or non life. Because there's some tiny space in me that is a little fogged over and in the fog when I put myself in my mother's wheelchair, I say, maybe, just maybe it's worth sitting here all day.

But why EJ, why? Because Marvin couldn't just let you die. That's all there is. It's not really complicated. I know it and you know it. There was no way my father was going to let my mother, his wife of over forty years, die even if he had to do all the fighting for her.

Like the Schindlers fighting for Terri and Jason Torres fighting for Susan and her fetus.

But Jason Torres isn't really fighting for Susan and that is the whole very important point. And the Schindlers weren't really fighting for Terri and my father wasn't feeding my mother because she was hungry.

He was hungry, day after day, year after year. So hungry was my father sitting alone at night with all the lights out in the living room and the TV on loud with his beautiful wife—my mother—in her heavy metal wheel-chair, that he didn't know what else to do except pick up that fork and feed her and feed her and feed her until she died one night in her sleep with a very full stomach.

These are impossible situations. But we must find a way to talk about them. Because the truth is, you can't spend your life fighting somebody else's fight. They have to fight for themselves and when they're done fighting or trying to fight we have to let go.

When they say the word—that small tiny word that no one wants to ever hear. When they finally say it *outloud* or don't say it—the word. But you know deep down inside they would say the word, and are saying the word like the Pope—who they let go without His saying the word.

Can you hear them? Screaming now. I have to cover my ears it's so loud. I hear Terri, Edith Jeanne, and Susan. The silent sisterhood is screaming one big giant word. Louder, the loudest

scream in the whole wide world. A scream more powerful than a tsunami. The women are screaming, shrieking at the very top of their lungs. Can't you hear them. Shouting?

Listen.

The buckeye's finally popping. Pop. Pop. Pop. Wide open.

NOOOOOOOOOOOOOOOOOOOooooo.

I know you can hear them.

NOOOOOOOOOOOOOOOOOOOooooo.

Come on, say it with me. Don't leave them all alone.

On the count of three. One, two three.....

NOOOOOOOOOOOOOOOOOOOooooo.

PHOTOS

Photo on page 55: Edith Jeanne and Marvin in Florida, 1990.

Photo on page 57: Jyl Lynn and Edith Jeanne, 1981.

Photo on page 63: Jyl Lynn and Edith Jeanne at the Felman's 40th wedding anniversary, 1987.

Photos courtesy of the author.