

## **On Almost Becoming a Person**

**By Eugene Marcus**

(This speech was a keynote presentation at the FC Conference in Syracuse, NY, on May 5, 1998.)

What I want to talk about today is about life and fairy tales, and how you know which one you are in at the moment. Seems easy, doesn't it? But sometimes life becomes magical, confusing, and familiar all at once, just like a fairy tale. And so there are times I feel more like Pinocchio than I do like Eugene Marcus.

Never think that I regret this. Fairy-talking is a great way to pass big quantities of unused time. Telling ourselves stories may be relaxing, but it is not going to be a force to make things change. Unless we now move to more serious matters, we will be silenced as sure as Pinocchio on the shelf. Just telling our stories to ourselves changes nothing, but telling them to each other prepares us to be a force for changing the world.

Can we understand the meaning of FC as merely a way of communicating for those of us who were not speaking before? No, it is more than that by far. FC has been for us a great promise, and it has been both a kept promise and a broken one. FC has kept its promise to me that my contact with people would grow and make a more meaningful team of me and those people who care about me. Having friends who know me very well was always a dream, but is now a major part of my life. But FC early on came with a promise that if I could communicate I could control my own life. My experience has been that I can be very clear and very articulate and still be unable to make things change. Lets say that this has been a political awakening for me. Consider these not broken promises, but ones waiting to be kept. (This is not directed at specific people, but at the way we sell things we are excited about.)

Can this mean FC was not a good idea? No. FC is a way I got a shot at becoming a real live person.

It's vain to think that I am already a real person in the eyes of everyone. Real persons, I have found, aren't concerned with that. (If I had to wait for FC's biggest enemies to certify my reality, I would be sitting on a shelf with sawdust tears in my eyes.) No, being a real person in my own heart is what this is all about, and I am sometimes an even harder critic than anybody. So this speech, then, is about turning from a boy of wood to a real boy in my own heart.

All my life, I have been real to my parents. I took this for granted as a young man and as a child, but now I know how blessed I have been by this single simple reality. Can you imagine what it would be like to not be really real to your own parents?

I can.

I now meet people who believe the experts more than their own eyes, and I worry for their children. I worry that those parents will be like a Gepetto, who dreams of having a real child, but who cannot hear the loving beat of the new heart inside the stiff wooden boy. And I worry that the boy, always talked about as wood instead of real, will believe that the new heart is not real either, if the wait for good news becomes too long.

And so: if you need to be real in your own eyes to be real, and you need to be real in your parents' eyes to be real in your own eyes, and there are many experts devoting themselves to showing just how hollow and wooden you are, what cause do we have for new hope in our new, soft and scared hearts? The answer to that question is one I hope to begin today.

All people are real, in the deepest sense of that word. That means that there is no such thing as a non-human human. But if you look around this room, you will see people who look at least non-standard. And that is where the problem begins. We live in a country where image is kind of a reality more real than reality. My main answer to that is: I don't need surgery to make me real any more than a beautiful woman "really" needs her eyelids sewn back. The fact that I think I do and she thinks she does is more fairy tale than real. Eagerness to be like others didn't make Pinocchio real -- it turned him into a donkey! And eagerness by parents to cure autism or retardation or compulsiveness will not drive great distances toward the final solution to the actual problem. Because the person who believes, "I will be real when I am normal," will always be almost a person, but will never make it all the way.

So when did I know I was real? That began some time ago. It started when my parents read to me as a child, and when they went to make sure somebody would treat me very right at school. Announcing to the school, "I expect you to treat my son like everybody else," is an announcement that goes straight to the son's heart. And the son that hears this from his parents is armed against professional name calling and bullying, (or what you call making diagnosis and behavior planning).

Another milestone in making me aware of myself was the new tsunami of reality that came with FC. My flood of experience has allowed me to be respectful to friends and enemies alike. Let me explain this better. I used to think that people who made me do demeaning childish things against my wishes were enemies, and my life was like an occupied country. I see now that much less were they enemies, much more were we frightened strangers to each other. How I now understand it keeps me from making my oppressors into my enemies. There is still much to be done to make them just friends or even colleagues, but at least I no longer hate them. The experience of FC has showed me that each of you and I are so much alike that only superficial

things stand between us. Great care is needed so that we do not become overwhelmed by this superficiality. However, my ability to overcome appearances has depended on FC, and on the common effort of those of us who keep using it.

With all of the just demands here I make of myself, there are also the demands I make of the professional workers in my world. Sensing the truth about the way that I have been thought of by professionals is a humbling and infuriating and nerve-wracking experience. Humbling, because we start out believing what they tell us about ourselves. Infuriating, as we realize we have been lied to. And nerve-wracking, when we know we aren't going to be "normal" even when the prejudice is over.

Lets work to understand the role some professionals have played in making us lose our ability to be real to ourselves. They have unethically acted like they knew a secret about us that we didn't know about ourselves. How can such a thing really be? Most professionals will never tell us, "This is what I think." Instead, they say "This is what I know." That is dishonest and harmful. In fact, we usually know better than they do what is happening for us, and are only handicapped by not being listened to, or being considered deluded. We need a new kind of relationship, we and our professional mentors, if we are going to make the better world they want as much as we do. Work will begin soon after they admit their limitations, (and that is something in which we are the experts, not them!)

Thinking about becoming real made me realize that my definition of what "real" meant was part of what held me back. What does "real" mean to you? It might mean "not pretending," (like butter is real and margarine isn't). And it might mean "typical," (like many people think breathing through your nose is real and breathing with your mouth open isn't). But what if the only way to be really typical, like common people, is to be really pretending, acting rather than just being? That is the dilemma my life centers on these days. Great help in this dilemma is available from each other. My friends who are not autistic have helped me know what is typical without demanding I be typical. That is a great help to me. And my friends who are autistic have showed me how many different packages you can be wrapped in and still have a beautiful inside. We can provide good support for each other only if we have the means to get together on our own terms.

I am not sure what that means for everyone, but for me it means being able to take time without having to keep a schedule. When we have free time, good facilitators and staff, and real trust, we can build each others' confidence. Keeping confidence alive is the hardest thing, and it is the thing we need most from each other.

Before we decide we are real, one other thing is needed too. You think that we all want to be real, but many of us see real life every day and really don't think it looks so wonderful up close. We see people who are real but frightened, real but unhappy, real but alone. So sometimes we need a bigger reason to become real than just because it's what we always wanted. The being real

I am talking about here is a bigger one than either definition I made before. This being real means being yourself as a political statement, being yourself as a way of trusting God, or being yourself as a way of making sure you are not dissolved into nothing but other peoples' expectational thinking. I am talking here about being real as a person dear to yourself just as you are.

Getting to this place in my own life is not an easy thing, and it is not a shameful thing, really, if any of us sometimes feel maybe the bastards were right after all. But that feeling fades and the truth remains. Felt truth, of course, keeps us going regardless of whether it can be proved. But truth is always a belief that remains after a feeling of doubt and despair has gone.

So we come once more to the riddle, when is a boy of wood a real boy? (Because you and Pinocchio and Gepetto and Jiminy Cricket might all have different answers.) We come near to the answer when we are open to the truth that we see a child before us who needs love. We are nearer still when we know we don't have to understand somebody to know he is real. And we are nearest when we come to the realization that the question of being real is not needed when there is love there. At this point we are real to ourselves and real to each other, and the Blue Fairy will never leave us again.

Before finishing my talk today, I have one more thing I want to make sure you are thinking about. That thing is political action. We are all together here in Syracuse, and that is an opportunity that must not be wasted. Trying to convince the damn stupid media and the cold calculating professionals is more than one woman or man can do (though Sue Rubin and Sharisa Kochmeister might come close). But think of the power if we put our weird voices and scary bodies on the picket line. Think of the power if we write a major article together. Think of what would happen if every time one of us is silenced, we send letters of support to our friend and letters of angry power to the silencer. Think of what would happen if our loud unified shout was heard in the land.

Thinking about these things is perhaps as far as we will get today, but please... let's move from the world of thoughts, where we have all spent far too long, to the world of full adventurous action. No fairy story will ever be as exciting as the one we create with our own magic wands, which we already hold in our powerful typing hands.