

## **FAMILY REFLECTIONS: A DIALOGUE WITH MY MOTHER**

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**On the 12th of this month our nation is going to commemorate the 40th anniversary of the 1955 announcement that the Salk vaccine was safe and effective. Jonas Salk will travel to the University of Michigan to be honored as the scientist who conquered the deadly polio virus. The world will be asked to stop and reflect for a moment on this historic event. We will be invited to visualize Salk's intellectual and interpersonal struggles, the dedication and tenacity that led him to the completion of his goal and then the formal proclamation that the field trials on over 1 million school children had finally proven his vaccine's power over polio.**

**Being involved with the March of Dimes in planning this event has provided me with a new opportunity to reflect on the significance of this celebration for me as a polio survivor. What good does looking back really do? 1955 is long-gone. What can be learned from this sanctioned time of reflection? I got polio. I wasn't saved from it by the vaccine. It came 3 years too late for me! Am I supposed to thank Dr. Salk for annihilating people like me from occupying a place in our global society? I can't and won't do that.**

**And I've realized recently that that's not the point. As part of the ceremony, polio survivors from around the country have been asked not only to attend, but to share their**

personal family stories for publication in the commemorative book that will honor us, along with Dr. Salk. You see, we too, have conquered this deadly virus in our own right--in our own very complex and private ways. We have set goals, fought, struggled, worked hard to compete and live well in a culture organized for its non-disabled members. And we have become productive members of that society. Even today, as we gather in these rooms, we continue our historic work as we pioneer to conquer the late effects of polio.

Looking back to discover how we have, as a group, established a place for ourselves in American history is a great opportunity that this 40th anniversary ceremony offers. It's a time to acclaim the 1.6 million of us who are still living in America for how we have lived and what we have achieved. We have important lessons to teach generations to come about growing old gracefully, physical and social adaptation, personal empowerment, spirituality, independence versus interdependence, and civil rights, to name a few.

The 40th anniversary of the Salk victory also can prompt us into a time of individual introspection. It invites an opportunity for each of us to review our private lifecourse with polio--to open our own personal histories for a time of recollection and perhaps a little reconstruction.

My personal way of glancing back to reflect on past events this winter has been to begin a new dialogue with my mother. I asked if she would be willing to capture some of our history on paper. She was surprised and pleased to be of help, so we have begun to write letters to each other. Lincoln Schuster, the American publisher once said "letters remind us that history was once real life." As we write back and forth, Mom and I are taking time to re-examine our "once real life" polio experience together. It's giving us an

opportunity to re-confirm and slightly re-order our lifelong views. It's helped me to see more clearly from my mid-life vantage point, our roles as mother and daughter, our personal strengths and human limitations. I've learned that Mom was the one who made things work. She provided the family with emotional strength through the polio crises. She was solution-oriented and spent very little time dwelling on the problem. There were times though, when she felt helpless. Like the time when she was forced to abandon her paralyzed 4-year-old child at the hospital. She writes to me in one letter, "all we could do was leave you there and face what was yet to come. Before we left you you said 'will you give me a kiss?' Of course we did, but we thought of the danger to ourselves because polio was so contagious. We believed that the kiss was more important than our fear."

My curiosity about the past and her recounting have driven home the notion that this disability also intimately affected and permanently shaped all of the people around me-- my brother and sisters, my father, my teachers, my employers, my doctors and therapists, my close friends, but especially my parents. It is true that so many people who touched our lives should also be admired and honored on April 12th along with Dr. Salk.

What good does looking back 40 years really do? I didn't know until I started this mid-life journey into my past. Then the insights began to emerge in a new way. In our dialogue, Mom and I both have come to agree that its good to talk about our past and validate how its been for each other so we can move into the new phases of our lives that are waiting to open up for each of us. Some things are ugly and scary and too private to share publicly. Some things are more heartwarming than I had remembered. With the hope that you may be encouraged to take some time to talk with those you love the most about

**your experience together with polio, Mom and I would like to share our first 2 letters with you today. We hope that our starting to dialogue may encourage each of you to use history to your advantage as you ask: "What was it really like? What can the past 40 years teach us? Where are we right now?"**

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**January 27, 1995**

**Dear Mom,**

**Here we are in 1995. I'm a successful professional woman--single, creative and well-travelled. You and Dad are in your 70s, successful, retired with 4 kids and 2 grandchildren. As I take this moment to reflect on our 47 years together as a family, I'm wondering if you'd help me understand what it was really like having me for a daughter. How was it for you to have a child--a healthy, pretty firstborn--who at the age of 4 was suddenly devastated, almost killed, by polio?**

**Remember the doctors only gave me ten days to live? They almost put me in an iron lung. I could only move one finger. In the hospital for nine months right after the acute attack, I recall the hot, wet wool towels they laid on my limp legs every day. Remember when one nurse scalded me? I still flinch at the smell of steamy wet wool. Remember the day I took my first steps as I re-learned how to walk in stiff metal braces, propped up with little wooden crutches? We were all so proud as I posed for a snapshot with my physical therapist. What were those first nine months like for you back in 1952? Thirty miles from the hospital, you were only allowed to see me on Sunday and you hadn't yet bought your first car. What did you say to yourselves to endure the emotional pain of knowing your eldest daughter who now hobbled about the best she could would often be stared at, falsely perceived, and would need special help throughout the course of her life? Did you ever take time to grieve the loss of your healthy able-bodied little girl? Did you ask "why, God, why?" "Could we have done anything differently to prevent this tragedy? Is it our fault?**

Maybe we kept the house too clean so we weren't immune enough to the virus. Should we have stayed home from the beach that day that we think I got polio?"

How could you afford all the medical bills? Nine months of rehabilitation, ten years of monthly trips to the orthopedic clinic, five major surgeries, new braces and crutches? How did Dad feel having to take off work one day every month to drive me to see the doctors in downtown Detroit? Did his bosses really understand? Weren't there times when you hated me because I was so much extra work?

Mom, remember how people raised their eyebrows and thought you were mean to me because you used to make me do things for myself? You'd say "go get it yourself!" or laugh when I'd fall down and flip me a chair and tell me to "get up!" Remember how I slipped and fell on a wet cigar butt in front of the drug store? We still laugh about that and one of your standard farewells to me after a visit is "well, watch out for old wet cigar butts!" We laughed through a lot of ups and downs. I recall working so hard to come back from polio. You taught me that if you can't do things the way everybody else does, a different way will work just as well too.

And so the years have passed. You continued raising your three younger children and I became pretty independent. Completed college, taught school, lived on my own, supported myself and got on with life.

But then all hell broke loose again. At the age of 35, I got the late effects of polio. While working on my Masters degree and working my way through grad school, I began to experience debilitating new pain, weakness and fatigue. One devastation led to another and I ended up back living with you and Dad--in more pain, no job, no money, with no

knowledge of what was happening to my body. A serious life crisis. Five different doctors all told me something different. None of us expected this harsh turn of events. Polio, the monster we had beat once, had returned, nastier than ever.

We were alarmed, baffled, frustrated, angry and damned scared. I got quite depressed at first. I remember you said, "Sunny, all we have to give you is a place to stay. You have to figure the rest out yourself. We are only just able to take care of ourselves now that we're older and your Dad has retired."

That comeback took almost 8 years. New rehabilitation, a post-polio support group, creating a customized job for myself that would allow me to get back in the mainstream and also help others who were experiencing the late effects of polio. It was a lot of work just like the original polio rehabilitation was. New serious instructions about pacing myself, new braces and crutches, a wheelchair for the first time and a bunch of new coping tactics.

As a result of those late effects, we've started to have reflective discussions about our life-long polio experience together--how each of us saw it. I remember you teaching me to be as independent as possible, to be persistent, to treat my disability as an inconvenience rather than a major blockade. I remember Mom saying "do you control the situation or does it control you?" You told me that I was "just like the other kids except that I walked a little slower." Dad told me it was important for me to have several brothers and sisters, so I'd have a life-long support network. But what's the rest of our truth? Will you tell me what it was like for you? I'd appreciate your insight.

Love,

Sunny

February 1, 1995

Dear Sunny,

Thank you for your most interesting letter and the questions it presented to me. As you well know, I'm not very good at "looking back" because I'm more interested in "looking ahead." I have never been disappointed for very long because any negative can become a positive. It's all in the way that you perceive the situation.

You were born beautiful and intelligent, cuddly and cute, and loving and loved. Nothing has changed in all these years. You are still "Sunny" and that's who you'll always be. We've always been "best friends."

As a child, you commanded respect from the whole family. Not only by your birth position, the first born, but by your constant accomplishments and your willingness to help us all. You were a constant source of pride for your father and me.

We never felt sorry for ourselves because we were too thankful that we still had you (with just a few strings attached). We needed you. Had you been taken away, we would have never felt whole again.

When polio struck you and your brother we were horrified, but we knew what we had to do. We had some insurance and the "March of Dimes" helped us through most of the financial problems we faced.

Having you in hospitals for so long was rough because we had to rearrange our lives somewhat. We had to have sitters for the other kids, so we could come to visit you. Once we brought your little brother out to Sigma Gamma Hospital with us so you could see him from your window and he could see you. We wanted to make sure your bonds stayed



strong. They did, because Scott always felt needed and he became very protective in a good many ways.

I will never forget one of your childhood observations and how it could relate to your present job--that of diversity awareness. At Sigma Gamma there was a delightful black lady who cared for you and seemed to be very interested in you. She made everyone around her feel good. One day you said to me "Mama, I think God loved her a lot because he took the time to color her with his crayons." You were 5.

When you finally came home to stay, we had moved into a house that was easier for you to get around in. Dad made you a little chair on a platform with casters on the bottom so you could get around when you didn't have your braces on. I never would have a wheelchair in the house because I didn't want you to become dependent upon it, even though it would have come in handy a lot of the time.

The new house had a bedroom and bath on the main floor. The master bedroom was upstairs so we had an intercom we called the "squawk box," installed so we could hear you at night. Sometimes, we would have to come downstairs and help you turn over because your abdomen and back were still weak. Dad and I would take turns answering the calls. We were always busy making things "better" for everyone.

I always wanted you to be happy and to have little goals to achieve, so we would go to Ona Craft Shop every week and get crafts we could all do together. It was good for your hands and it helped to instil creativity and a sense of independence in you. "Busy hands make happy hearts."

Life has been good and even though we've had problems, we've managed to see the

**light at the end of the tunnel most of the time.**

**We wanted you to go to public school and be with the real world since that's the one you'll always live in. It taught you that you could control the way you were perceived by others. You were special, but not too special.**

**Now, that Dad and I are in the twilight of our lives, our plans are coming to pass and you are as independent as we planned for you to be. We plan to help you as long as we can and as long as we are able, but there will come a time when we will be gone, just as our parents have left us. We mourned for awhile, but life goes on for you. Keep the best of us in your heart and always see the best in those around you. Remember what your grandma, Nana, said-- "Life is like a game of cards. It's not the hand you're dealt that counts. It's how you play the cards that's most important."**

**Love,**

**Mom**

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**Is there someone in your life you'd like to talk with about the history of your polio experience? If there is, why not do it while there's still time?**