

Excerpted from Chapter 1 of **A Parent's Guide to Down Syndrome: Toward A Brighter Future, Revised Edition**, by Siegfried M. Pueschel, M.D., Ph.D., J.D., M.P.H., with invited contributors.

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From Parent to Parent

As we begin the new millennium, human expectations for the quality of life are higher than every before. Hopes and dreams soar at the impending birth of a new baby. When we are told, however, that our baby has Down syndrome and we must reshape our hopes and dreams, our original parental sorrows remain unchanged. It is perfectly normal to grieve.

Of all the joys and sorrows of a lifetime, no event was ever more traumatic for my husband and me than the birth of Martha, our daughter who has Down syndrome. We were shocked, shattered, and bewildered. No woman ever really expects to give birth to a child with disabilities. Prior to Martha's birth, mental retardation had simply been a statistic to us — something that happens to someone else; yet no child has ever taught us so much or brought us so much love.

Today, because of the advances in prenatal testing and screening, it is not unusual for parents to know prior to the birth of their baby that they will have a child with Down syndrome. Many choose to continue the pregnancy, realizing that no child, at any stage in life, comes with a written guarantee of perfection. These are parents of great courage, and in the months preceding their child's birth, many resources are available to them to help plan for their child's optimal care. They may wish to speak to other parents and be assured that it is alright to grieve for the loss of the child of their dreams.

If you are new parent of a baby with Down syndrome, then I can share the deep sorrow you feel in every fiber of your being, the aching disappointment, the hurt pride, and the terrible fear of the unknown. But I can tell you from personal experiences that having known this ultimate sorrow, you will soon learn to cope better with every phase of life. You *will* be happy once again, and through your child you will receive undreamed of love, joy, and satisfaction.

If you are the parent of an older child with Down syndrome, then you have probably already formed a special bond with other parents of children with special needs, parents who have shared the same intense joys and sorrows. If you are a special educator or work in human services, then you, too, must be elated at the progress that has occurred for individuals with mental retardation. Your continued encouragement

and reinforcement and your willingness to see each child as a unique and valuable human being can add immeasurable dimensions to the lives of children with special needs and to the lives of their families.

Life cannot remain the same. The decisions to choose a profession or a new career, to marry, or to have a child — all important milestones in life — imply change. The addition of a child with Down syndrome to a family precipitates even more rapid change, but the loving support you will meet at each phase will be an enriching experience.

My first fear was for our marriage. If it had been a shaky commitment, our new child could have provided us with an opportunity to blame each other or to make excuses for never finding time for self, each other, careers, or friends. But if you work at it, this special child can be the opportunity for better communication and for finding new courage and love in your partner. Personally, I have never appreciated my husband so much; the feeling of mutual support has enhanced our marriage.

I feared for our other four children. I wanted to give each of them enough time so that they would not feel neglected or harbor unspoken feelings of shame or resentment. Their response, their potential for love, has overwhelmed us. They have given us courage in so many ways, and in turn they have not been cheated but enriched. Together, we all have learned the dignity and worth of each human being.

I feared so for our new little child, Martha. This was surely not the life I had intended to give her. But I have learned that her life is very precious, that she has been singularly happy and loves unquestioningly to a degree that makes me wonder just what constitutes "normality." She truly has been a joy to us.

Compared with the bleak future that formerly awaited a child with mental retardation, remarkable progress has been made since the 1970s for the child with special needs — surely more progress than the 100 years preceding. The public in general has experienced a new awareness, sensitivity, and compassion. Programs and services are mandated by law to guide and support us and our children from their birth through their adult years: We as parents must work to ensure their satisfactory implementation.

Support groups exist everywhere and are invaluable to new parents. We were very fortunate to join a marvelous program for children with Down syndrome, run by professionals whose expertise, love, and respect for every human being have guided us through our most difficult days. Fortunately, similar human services and guidance programs to assist you in planning for your child's development now exist all over the United States. During Martha's early years, the professionals in our program became

far more than advisers to us: They became friends to whom we will always be grateful.

One of the gifts our daughter's birth has brought us is a wonderful network of friendships with other parents who have successfully combined their own careers with the loving care of special children. We never would have had the opportunity to know these friends without Martha. They have worked unflinchingly against what we once felt to be great odds. Their courage has uplifted us and caused us to look more realistically at life's true values. Lifelong friendships have become even richer as our friends seem to share a special pride in Martha's accomplishments. I like to think that the entire community has profited. Their kindness has overwhelmed us.

If your child is very young, you will soon learn that the child with Down syndrome does almost everything a typical child does but more slowly. With love and understanding, our children can achieve many things that once were unexpected of them. They will walk, and run, and laugh, and tell you when they are thirsty and hungry. They usually will be able to read and write, will love school and music, and will delight in travel. They will swim; bowl; take ballet, sailing, horseback riding, and piano lessons; join Boy Scouts or Girl Scouts; go to camp; and receive First Communion, Confirmation, or Bar Mitzvah in addition to so many other things we might wish for all our children. They will respond well to gentle discipline. They will have a definite sense of humor and a great sense of the ridiculous and will learn so much from socialization and imitation. Their sensitivity will even console *us* if we are sad. They will be bundles of mischief, imps with sticky fingers, and, only incidentally, children who happen to have disabilities. Unlike our other children, they will love us unquestioningly and unconditionally with a resolve and a tenacity that almost defy understanding.

As for Martha herself, she has been a constant source of joy in our lives. She has always been placid and gentle but has maintained a quiet enthusiasm and gratitude for the simplest favor. She has laughed easily and often, and her courage and happiness teach me so much about life's true values. During the school years, she willingly assumed responsibility homework and chores, even more readily than her brothers and sisters! She attended our local high school, where she experienced marvelously dedicated teachers and teacher assistants whose enthusiasm was transmitted into a positive learning atmosphere. As mandated by law through the Individuals with Disabilities Education ACT (IDEA) of 1990 (PL 101-476) and the IDEA Amendments of 1997 (PL 105-17) and with continual reinforcement by her parents and siblings, Martha remained in high school until she was 21. Because one of her strengths was reading, for a full year before her graduation, she job-trained with an enthusiastic job coach at the children's division of our local public library, where she sorted books alphabetically and returned them to their shelves. She was very happy to

continue this work after her graduation, and we feel proud that she has made a definite, dignified contribution to the community.

What do we as parents wish for our children's futures? I think the most valuable thing we can give is complete acceptance of them just as they are and a desire to make them as happy, caring, and independent as possible. From the community, we ask for compassion — not pity — and the chance for them to prove themselves as fully as possible while being accorded all the rights of a human being within their capabilities. Our greatest hope is that someday when we are no longer here, our children may live as independently as possible in a carefully supervised environment within the community where they may know the joys of warm friendships, the dignity of self-worth, and the usefulness of work in a satisfying atmosphere.

As parents, we have learned that there is little more we can wish for any of our children but that they develop their potential to the best of their abilities. In the end, all the material accomplishments of this world won't matter much at all. What will endure is the quality of love we have given each other. For us, what seemed like the tragedy of our lives has become our richest and most fulfilling opportunity. Indeed, we have been richly blessed.