The Disabled Woman’s Guide to Pregnancy and Birth

Judith Rogers
THE DISABLED WOMAN’S GUIDE TO PREGNANCY AND BIRTH
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Demos

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I dedicate this book to the source of its inspiration: my children, Anya and Ari.

I also want to thank all of the women I interviewed, who freely gave of their time and of themselves.
"I wanted to have a child so I could be part of the flow of history."

MICHELLE
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I have been disabled since birth. Being disabled meant being without a role model. There was no person or book I could turn to for information about crucial issues. Most of the writing about disabilities focused on disabled children, and this continues to be true today. Yet, a disabled child grows into a disabled adult with questions of her own. In recent years, there has been greater acceptance of the sexuality of disabled people and more attention has been paid to their needs. The next step has to be validation of the reproductive capacity of disabled women. This validation is especially important now that social services and special adaptive equipment offer new solutions to the problems of pregnancy, labor, delivery, and child-rearing.

When I became pregnant, I again found that there was hardly any literature concerning my particular needs. I searched the abundant material on pregnancy, labor, and delivery, but found little that was relevant to the concerns of the disabled. Most of what was available was limited to single examples in technical journals, personal accounts, and vague generalizations.

At that time I was working at the Center for Independent Living, an organization run for and by disabled people. Finally, I had found role models and peers to share my concerns with, including one co-worker who had been pregnant. At the same time I was receiving calls from other pregnant, disabled women with unanswered questions. I began to see that the best way for women with disabilities to find answers would be to share their experiences. In order to gather as much useful information as possible, I compiled a questionnaire that was based on a series of in-depth conferences with friends and colleagues. I posted notices in pediatric clinics, centers for the disabled, and at disability conferences. Some people heard about the project by word of mouth. Finally, thirty-six women answered the questionnaires in personal interviews. Their responses are at the heart of this book.
While I was conducting the interviews, I supplemented my knowledge about disability by learning more about pregnancy. I trained as a birthing instructor and taught for 4 years. I added to my practical knowledge of pregnancy by questioning my students about their experiences and by attending numerous births. After the interviews of mothers with disabilities were completed, Molleen Matsumura, my co-author on the first edition, and I conducted formal research on pregnancy, disability, and the interaction of pregnancy and disability.

Since the first edition was published in 1991, more has been written on pregnancy and disability. Moreover, working at Through the Looking Glass (TLG) has been invaluable for many reasons. TLG has given me the opportunity to have contact with disabled parents. In addition to doing research and creating adaptive equipment, TLG is the foremost agency in the country conducting research and providing direct services for parents with disabilities. An extensive review of the literature, and interviews with experts in the fields of obstetrics, genetic counseling, physical therapy, nutrition, nursing, psychiatry, neurology, emergency medicine, anesthesiology, and rehabilitation were done for both editions.

All of the women I interviewed were physically disabled. Some of them had a hidden disability, such as thoracic outlet syndrome or fibromyalgia. They represented a true cross section of the community. They were married, divorced, or single mothers; some were full-time homemakers, professionals, white-collar workers, or women needing public assistance; they were lesbian and heterosexual; and there were women of different races and religions. Some of the women who were interviewed for the first edition had given birth 30 years before, but most of the women in this second edition were new mothers at the time the interviews were conducted. Most interviews took place over the telephone. I was careful to include women with a variety of disabilities. The degree of disability varied among those with the same diagnosis. It is interesting that there was more similarity among women with the same degree of disability than among women with the same type of disability.

The most important lesson to be learned from this study is that disabled pregnant women have much the same concerns as all pregnant women. This became even clearer when Molleen, who is able-bodied, kept commenting as she read the material I had gathered, "That's exactly how I felt when I was pregnant!"

Although this book includes much information that will be important to women with disabilities, any pregnant woman may benefit from the problem-solving approaches and specific solutions suggested here. (A personal favorite is sleeping on satin sheets to prevent leg cramps.)

Careful attention has been given to differentiating between the changes and discomforts that are common in pregnancy, and those that are disability-related. In general, disabled women experience many of the same changes as able-bodied women, but they are often unsure whether what they are feeling is disability-related, which can be a source of anxiety.
Health professionals will also find this book valuable because they will learn about the problems their students and patients have been hesitant to express. Some of the information presented here may also suggest new directions for research. Often, simply sharing this book with patients can be helpful.

The opening chapter describes the pregnancies of the women who were interviewed, and underscores how much women with different disabilities have in common. Included are simple explanations of the different types of disability, and descriptions of the physical changes each woman experienced during each of her pregnancies. Finally, it offers the insights the women shared about pregnancy and disability, including their ideas for building cooperation between the pregnant woman and her health care team, and their insistence that a pregnant woman with disabilities be seen primarily as a prospective mother.

Chapters 2 through 4 discuss the many questions that must be answered by a woman who is considering having children. It examines not only the effects on the health of mother and child, but also other practical and emotional concerns, such as “How would I feel about giving birth to a disabled child?” and “How will having children affect my marriage?” The suggested questions that women can ask themselves, their doctors, and their counselors are just as important as medical information. They will enable each woman to make the decisions that are best for her.

Chapter 5 contains advice on how to select a doctor and hospital, what specialists might need to be consulted, and how to assure cooperation and communication among care providers. Again, questions are presented that women can ask in order to make sure their needs are met.

Chapters 6 and 7 focus on prenatal nutrition and exercise and give suggestions on how to maintain health and comfort. The chapter on nutrition explains the role of various nutrients, giving attention to the special concerns of disabled women. Also included is an explanation as to why it is important to gain weight. The chapter on exercise contains exercises that have been adapted for varying levels of disability, so even a woman with limited mobility can maintain flexibility and good circulation.

Chapters 8 through 10 on the three trimesters of pregnancy discuss the physical changes of pregnancy, what to expect during office visits, pregnancy discomforts and ways of coping with them, fetal development, routine and special medical procedures, possible complications, and emotional concerns. These chapters also include a discussion of the special concerns for each trimester. For example, the chapter on the second trimester includes suggestions for choosing a good birthing class. The special concerns of disabled women are addressed throughout the chapters; for example, the different ways some of the interviewees managed to measure their weight, and how to instruct medical office staff in assisting with a transfer from wheelchair to examining table. Again, there are lists of questions that women can ask to help them understand what is happening and get the information they need to choose appropriate medical care.

Chapter 11 describes the course of labor and delivery, ways of coping with the discomforts of labor, and possible complications and how they might be treated. It begins
by explaining how to recognize that labor has begun, including a description of the symptoms of labor that might be experienced by women who have reduced sensation. Included are suggestions for relieving muscle spasms and finding alternate positions for giving birth.

Caesarean birth is covered in Chapter 12, and may be reassuring reading for many women with disabilities, who often assume that they will have to give birth surgically. This chapter begins with an explanation of the reasons for caesarean delivery, including a discussion of the concerns of disabled women who are considering this procedure. Next is a description of what happens during caesarean delivery, including what the mother can expect to feel, what happens in the recovery room just after surgery, and recovery and self-care during the weeks following caesarean birth. Special attention is given to the effect of caesarean delivery on mobility and other disability symptoms. The chapter closes with a discussion of vaginal birth after caesarean section, including the comments of two interviewees who gave birth in this way.

The closing chapter describes what women experience during the postpartum period, the 6 weeks after birth during which their bodies return to a pre-pregnant state. It discusses the usual physical changes, variations that may be experienced by women with disabilities, signs and symptoms of infection and other problems, suggestions for self-care, and information about birth control methods. Some of the most important changes at this time are psychological and there is considerable discussion of these issues, including changes in the sexual relationship. This chapter also contains information that will help women decide whether to breast- or bottle-feed their babies, and suggestions for breast care and breast-feeding. It ends with a description of some of TLG’s research on equipment, and techniques for making childcare easier for parents with disabilities.

While this book is meant to be a practical guide to pregnancy, the author hopes, most of all, that it will encourage women with disabilities to enjoy their pregnancies. Most of the interviewees were glad they had their children—whether or not they would choose to become pregnant again. Pregnancy is an exciting time. If this book helps you understand the process, if it leads you to try other people’s ideas and inspires you to try some of your own, if it can be like a friend who is sharing your excitement—then it is doing what it is meant to do.

Judi Rogers
I acknowledge Through The Looking Glass for providing me with vital experiences and information on parenting, as well as giving me an opportunity to have contact with thirty-four of the ninety women.

I also acknowledge the wonderful support I received from my husband and friends, who were both editors and consultants. Their names are in alphabetical order, because they all made important contributions: Liane Abrams; Barbara Finnin; Pam Inbar-Hansen, MSPT; Johanna Kraemer; Stephanie Miyashiro; Helen Neville; John Neville; Corbett O’Toole; Ken Stanton, RN PhD; and Dr. Michelle Wolfe.

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Meet the Experts: The Experiences of Ninety Women

This book tells the stories of ninety women with disabilities who chose to have children and who were willing to share their experiences of pregnancy through the postpartum period. Unlike most women, who experience social and emotional pressure to have children, disabled women are under pressure not to have children. Yet, disabled women feel the same needs as other women to have children. I support their right to choose motherhood, and offer these primary recommendations:

Take A Positive Approach

The first recommendation concerns the importance of taking a positive approach to the pregnancy of a disabled woman. All of the interviewees encourage other disabled women to have children. For example, in spite of postpartum exacerbations of symptoms related to thoracic outlet syndrome (TOS), Taryn Dion\(^1\) encouraged other women with TOS to become mothers. But she stressed that it is important to get help immediately after birth. Moreover, Taryn Dion thought it was important to have a realistic image of mothering. The interviewees did not deny the potential for problems. Sharon spoke for the whole group when she said, “It may take a toll on your body. You will have to decide if you want to make the sacrifice.” As Portia commented, “Pregnancy, labor, and delivery are just the steps you go through to reach the goal of being a parent.” Several women felt they had been too fearful and stressed the importance of enjoying pregnancy. Others commented that after they had learned what to expect during a first pregnancy they worried less during subsequent pregnancies.

\(^1\) Throughout this book we make reference to the ninety women by pseudonym. They will be individually introduced later in Chapter 1; their detailed pregnancy histories can be found in Appendix A.
In general, the women who were interviewed said they had expected more problems and discomforts than they actually experienced; some even felt better than usual while they were pregnant. The problems that many of these women experienced were not substantially different from those experienced by other women, although mobility impairment was worse for disabled women.

### Make Pregnancy the Primary Concern

The second recommendation is that a woman with disabilities be seen primarily as a pregnant woman—both in her own mind and in the mind of her physician.

In their advice to obstetricians, many of the interviewees emphasized their desire to be treated “just like everyone else.” For example, Arlene said, “Be open-minded. I am just like everyone else: a woman who is having a baby.” Cheryl said, “Treat me like a woman first, and then secondly as a woman with a disability.” Much of the advice our interviewees offered to other disabled women centered on ordinary pregnancy concerns: “Try to have your baby vaginally” (Celeste). “Get two people to go in as labor coaches. That way one person can be a back-up” (Marsha). “I found the holistic approach helpful” (Samantha). “Find one nurse who will stay with you. I had my baby that way and I loved it” (Heather).

Yet, some women also expressed the feeling that their pregnancies were different from those experienced by able-bodied women. Some of the advice they offered stressed disability-related concerns: “Consult with specialists other than an obstetrician about the woman’s disabilities” (Sylvia). “Hold an in-service training for the obstetrics department and invite some disabled women to come in” (Stacy). “Even if you are only slightly disabled, make sure all the doctors involved know you are disabled” (Priscilla). “Be aware of your limitations and learn about adaptations” (Pam).

### Use the Team Approach

The third recommendation is that physicians follow the advice of disabled women and use a team approach to pregnancy and birth.

The pregnant woman, her obstetrician, and the disability specialists should all contribute to planning her care. Cooperation among the obstetrician, disability specialists, and the mother-to-be will ensure the best care. Holly said, “Both of my obstetricians called my neurosurgeon and made sure of what they should be looking for. By the time I got pregnant the second time, I had done a lot of my database work and was quite knowledgeable about pregnancy. I had my own ideas about what to do or not. My doctor was willing to listen to me, even though I’m not an M.D. He was willing to take my suggestions into consideration and consult a high-risk obstetrician. He said to me, ‘I’m the expert in delivering babies, but you are the expert on hydrocephalus and pregnancy.’ He knew I had studied quite a bit about it and he was open to my ideas. The doctor did something I thought was important—he contacted all of his on-call partners (only one worked in his office) and told them the whole story about my hydrocephalus and what to be careful about.”
Some of the interviewees suggested additional training for hospital personnel. Many of them had problems with postpartum nursing staff, which seemed to have difficulty imagining a disabled woman taking care of her baby. It is crucial that hospital staff be aware of how they can foster a “can do” attitude. An in-service can potentially help both the mother and hospital staff to become more confident. It is important to remember that supportive staff can help relieve a mother’s frustration and help her cope using practical solutions.

Create the Best Possible Outcome

Sensitivity and education are critical in preparing for pregnancy in advance: “Set up a support system before your baby is born” (Clara). “Get a physical exam before you get pregnant” (Hilary). “Have arrangements made before delivery for things like diapers, baby clothes, and furniture. Fill your freezer with enough dinners to last 3 months” (Stephanie). “Don’t wait until you’re in labor to find out how a medication could affect you” (Priscilla).

Introduction to the Interviewees

The women who were interviewed will be introduced in alphabetical order, according to their disability. The interviews were confidential and, therefore, each woman has been given a pseudonym that has the same initial as her type of disability. For example, Clara has cerebral palsy and Samantha has a spinal cord dysfunction. Because there are many disabilities that begin with the letter “S,” they have been subdivided into the following categories: spinal cord injury, spinal bifida, spinal tumor, and sacral agenesis. All of the interviewees whose pseudonyms begin with “S” are usually affected by numbness and paralysis, as well as urinary tract infections. To avoid confusion in the pseudonym code, the interviewees with short stature are listed under “D” for “dwarfism,” even though this is not the politically correct term. Five women were not fully interviewed but a few significant details of their stories have been included.

The tables in Appendix A list the specific physical changes each woman experienced during pregnancy. As a group, they reveal a broad range of possible responses to pregnancy. The tables cannot be used to predict what any one woman will experience, but rather show the kinds of changes an individual woman experienced. The experiences will differ, even for women with the same type of disability. For example, a few women with arthritis experienced an increase in joint pain during pregnancy, although most experienced a decrease. Variations such as these are the subject of continuing research and in the future there may be information that will help women better anticipate what they are likely to experience during pregnancy.

During their interviews, the women were asked to describe the changes they experienced. The tables emphasize discomforts rather than positive changes in order to help women plan for the discomforts of pregnancy. Many of the interviewees commented that they were delighted to find that for once their bodies were working right. They enjoyed looking pregnant, having larger breasts, being able to feel fetal movement, or being able to carry a baby to term.
The Women: Their Pregnancies and their Disabilities

AMNIOTIC BAND SYNDROME

Amniotic band syndrome is a disability that occurs in utero. There is a tear in the amniotic sac and strands of amniotic tissue either wrap around or attach to one or more limbs. These strands act like rubber bands. One or more extremities and/or digits do not develop in some fetuses.

Amanda

Amanda has amniotic band syndrome; her left arm ends at the elbow and her right arm is fused at the elbow. Her right hand has two fingers. Her left leg ends at the knee and her right leg is full length. She wears a prosthesis on her left leg and has arthritis in her left hip. Amanda was born with a type of hip problem that later causes some problems with wearing a leg prosthesis. Amanda primarily used crutches prior to her first pregnancy. She used a wheelchair infrequently prior to the birth of her first child. After the birth of her first child, she found that using a wheelchair to take care of her baby was easier. Amanda sometimes used her crutches after her first child was older. Since her second pregnancy, she has used a manual wheelchair full-time for mobility. She has found that using the chair is easier for both mobility and taking care of children. In retrospect, she said, “I would have been more selective about using crutches if I had known what I know now; for example, three-mile walks on crutches are not a good idea, even if you can physically do it. I never recovered all of the balance and flexibility that I had before my second pregnancy. In fact, I am going to physical therapy to see if I can regain more, as it has not returned on its own.”

AMPUTATION

Amputations have many causes, but the most common causes in women of pregnancy age are cancer and traumatic injury.

Amy

Amy was in an accident that not only resulted in a bilateral lower amputation, but she also broke her hip, pelvis, sacrum, and wrist. She also had a head injury. One of her legs is amputated above the knee and the other below the knee. She had trouble with transfers and her balance was affected during pregnancy. She had increased phantom and back pain. She experienced headaches and her backache worsened after her pregnancy.

Andrea

Andrea’s leg was amputated at the hip because of cancer. She usually uses crutches. She has carpal tunnel syndrome affecting both of her hands that started during her first pregnancy. This problem continued long after both of her pregnancies. She has arthritis in her
shoulders that started after her second pregnancy. Her balance also got worse during her first pregnancy.

Allison
Allison's leg was amputated below the knee following a car accident. She used a prosthesis for 10 years prior to getting pregnant. She was diagnosed with arthritis in both knees during the second trimester of her first pregnancy. Allison said, “The arthritis in my right knee was the most unbearable part of it. During both pregnancies I experienced dull pain during the night and my right knee locked into position. For example, when I was curled up asleep and tried to shift positions, my knee would be locked and it would be really painful to straighten it out. This problem went away after physical therapy and when I began taking anti-inflammatory drugs after pregnancy. It only happens rarely now.” Allison needed a new prosthesis after her second pregnancy. (See “Heather Ann” in Appendix A.)

ARTHROGRYPOSIS

Arthrogryposis is a condition that has different causes and affects the joints to different degrees. At least 30 percent of the cases of arthrogryposis have a genetic origin. The causes of the remaining 70 percent of cases vary greatly. There are two types of arthrogryposis. In neuropathic arthrogryposis, nerve function is damaged and, because the nerves cannot stimulate the muscles properly, muscle function is indirectly affected. In myopathic arthrogryposis, which is more common, the muscles are directly affected. In either case, arthrogryposis is characterized by multiple muscle contractures that limit movement of the joints. In some individuals, only a few joints are affected. In the most severe cases, nearly every joint is involved, including those of the spine and the jaw. The degree to which the range of motion is limited in the affected joints also varies among individuals. The affected muscles cannot develop normally; instead they atrophy (decreasing in mass and strength).

Arianna
Arianna does not know her type of arthrogryposis, although most of her joints are affected. She had her legs amputated below the knee. Her left hip is fused and she cannot lift her arms over her head.

Arlene
Arlene's myopathic arthrogryposis, which is not hereditary, affects all of her limbs. Her arm and leg muscles have atrophied and she has lordosis (swayback). She uses a wheelchair. Her usual disability-related problems include heartburn, poor circulation in the legs, and a persistent decubitus ulcer (pressure sore) under her thigh caused by inadequate padding in her wheelchair seating. Arlene had two miscarriages, possibly due to poor circulation. She delivered a child by caesarean section.
CEREbral Palsy

Cerebral palsy (CP) is a group of conditions caused by damage to the motor area of the brain. The damage can be prenatal, the result of birth trauma, a syndrome, or damage sustained during childhood. Symptoms vary depending on the site of the injury. From one to four limbs may be affected, trunk and head control may be affected as well. The different types of cerebral palsy are distinguished by the muscle tone and pattern of movement of the affected limb(s). A person may have more than one type of cerebral palsy. The three most common types are:

- **Spastic cerebral palsy.** This condition involves increased muscle tone, which results in the affected limb being stiff. In spastic diplegic (paraplegia), only the legs are involved. The legs are generally adducted (held close together). When the person walks, her legs tend to cross in a manner called “scissors gait.” In spastic hemiplegia, the leg and arm on one side are involved. The arm is generally held rigidly in a semiflexed (bent) position.
- **Athetoid cerebral palsy.** The major characteristics of this condition are involuntary, irregular, slow movements of the affected body part.
- **Ataxic cerebral palsy.** This condition involves a wide-based, unsteady gait and, often, reduced manual dexterity.
- **Mixed.** A person may have a combination of two types (such as spastic and athetoid).

Caitlin

Caitlin has left spastic hemiplegia (one side of her body is affected); although she feels that her right side is affected as well. Caitlin has a mullerian anomaly that is rare and happens during fetal development. During normal embryonic development, fusion occurs between the two mullerian ducts to form the vagina, cervix, and uterine body. Although this can result in various abnormalities, it caused Caitlin’s uterus to have a unilateral maturation and incomplete development of the ovarian duct on one side. This can also lead to urinary tract problems that are unrelated to cerebral palsy. She has two children.

Carla

Carla learned that she does not have cerebral palsy, but an extremely rare inherited condition known as familial spastic paraplegia. The two conditions have the same signs, and Carla was diagnosed as having cerebral palsy until some of her relatives developed similar signs and the genetic basis of their conditions were identified. Carla commented, “I’m so glad this information will be included in your book so that other people will know they might have an inherited problem.” Her walk is similar to those who have spastic diplegia cerebral palsy. She can walk two to five blocks and never used a wheelchair before pregnancy. Her usual disability-related problems include a limited walking range, back problems, difficulty in lifting and carrying, and muscle cramps.

Carla felt that on the whole, her second pregnancy was easier than her first because she had a better idea of what to expect and took a more flexible approach to her problems. She also said, “Taking care of a little kid had gotten me into better shape.”
back on her pregnancies, Carla commented, “I would have been more comfortable if I had started using a wheelchair in the second trimester.”

**Carol**
Carol has mild diplegic spastic and ataxic cerebral palsy. She used a cane to walk after her first pregnancy and during her second pregnancy. Her legs felt “rubbery” after the delivery of her first child which may have been caused by the epidural. This feeling diminished as she gradually stopped breast-feeding.

**Celeste**
All four of Celeste’s limbs are affected with spasticity. Her hand movements are somewhat awkward and she walks with a scissors gait. She used crutches before and during pregnancy, but now she uses a wheelchair. Celeste’s usual disability-related symptoms include edema of her ankles and feet, and muscle cramps in her hips.

**Charlotte**
Charlotte has a combination of athetoid and spastic cerebral palsy on her right side. Her right arm is less affected than her right hand. She often experiences spasms in both her right arm and leg. She used a three-prong cane to help with her balance during pregnancy. Charlotte took baclofen to help control her spasms prior to her pregnancy. After delivery, during which she was given an epidural, she experienced more spasms and tried both Botox® and phenol shots, which helped with her spasms.

**Cheryl**
All four of Cheryl’s limbs are slightly affected; although somewhat more on the left than on the right. Her balance is poor because she has both ataxia and athetosis. Cheryl’s usual disability-related problems include tension in her hands and abdominal muscles.

**Chloe**
Chloe has athetoid cerebral palsy that affects her body in all four of her limbs, trunk, and head. She also has a speech involvement and scoliosis (an S-shaped curvature of the spine). Chloe had open-heart surgery in childhood. She stopped being able to roll over during her pregnancy, and her respiration was affected.

**Christina**
Christina has spastic diplegia and walks without assistive equipment. Her usual disability-related problems are muscle spasms and backaches. She had one miscarriage due to placenta previa, which was not caused by her disability.

**Clara**
Clara has a combination of athetoid and spastic cerebral palsy on her left side. Her left arm is slightly affected and can be used as a helper. She walks with a limp and often
twists her left ankle, sometimes falling. Clara’s usual disability-related problems include infrequent muscle spasms, edema of her ankles if she walks too far in hot weather, and infrequent backaches.

Corrine

Corrine has spastic cerebral palsy on her left side. Her usual disability-related problems include aching in her upper back and difficulty walking. She has problems walking because it is hard for her to maintain her balance, and she frequently trips and falls. She rides a bicycle rather than walking for long distances.

Degenerative Disc Disease

Degenerative disc disease can happen in any part of the spine. There can be changes in the individual discs that cause pain from a damaged disc. This condition is quite variable in its nature and severity. With age, all people exhibit changes in their discs consistent with degeneration, but not all people develop symptoms (1).

Deirdre

Deirdre had a laminectomy and discectomy surgery 11 years before her pregnancy at L4-5. Laminectomy involves the removal of the bony structures on the side of each vertebra. A discectomy is a surgery that removes most of the disc. Deirdre had a discectomy at the L4-5. S1. Her cervical discs were herniated at the levels of 5, 6, and 7 seven years prior to her pregnancy. Her lumbar disc at L3 has also degenerated. Her symptoms include low back pain that affects both her legs and feet. She sometimes has pain running down her leg. Her legs and feet are sometimes numb, and this can affect her balance. She thought that bed rest had contributed to her being out of shape. In the process of rehabilitation, a new problem arose in both feet: plantar fascitis, which causes pain in the soles of the feet. Deirdre has upper extremity bilateral repetitive stress injury (RSI), which is shown as tendonitis. She experiences it as numbness and pain from her elbows to her fingertips. Her tendonitis can become easily aggravated and quite acute, resulting in her using her arms and hands less. Her shoulders also became deconditioned, as well, because she has limited use of her arms and hands. Deirdre had problems with balance and was immobilized the last 3 weeks of her pregnancy.

Dwarfism

Achondroplasia. Of the estimated two hundred types of dwarfism, achondroplasia is by far the most common, accounting for approximately half of all cases of profoundly short stature. The characteristics of achondroplasia are an average-size trunk, short arms and legs, and a slightly enlarged head and prominent forehead. Most people with achondroplasia are born to average-size parents, and they account for somewhere between one in 26,000 and one in 40,000 births. Adults, on average, are four feet tall. Young children
with achondroplasia must be examined for such potential problems as central apnea (the part of the brain that controls breathing does not start or maintain the breathing process); obstructive apnea (an obstruction of the airway such as enlarged tonsils and adenoids); and hydrocephalus.

Darlene
Darlene has achondroplasia dwarfism. She had hip pain prior to getting pregnant, but in spite of her hip pain she was physically active and enjoyed walking prior to pregnancy, during pregnancy, and postpartum. Her hip pain increased during pregnancy, but after the delivery her pain returned to the same level as before her pregnancy.

Diane
Diane also has achondroplasia dwarfism. She has had no back problems. She has four children.

Diastrophic Dysplasia. Diastrophic dysplasia is a relatively uncommon form of dwarfism (about one in 100,000 births). It was first differentiated in 1960. Before then, it had been thought to be a different form of achondroplasia. Diastrophic dysplasia is often characterized by short-limbed dwarfism. In some cases, a person may have cleft palate; clubfeet (atypical bone formation); hitchhiker’s thumb; and possibly ears with a cauliflower appearance. Serious orthopedic problems often require numerous surgical procedures. A normal lifespan is expected, but respiratory problems are sometimes present in infancy.

Denise
Denise has diastrophic dwarfism. This type of dwarfism is characterized by bony contractures caused by a decrease of sulfate in the bones, which results in minimal cartilage in the joints. This mainly affects the juncture of the large bone joints, including the femur (hip) and humerus (shoulder), but she has no contracture of the shoulders. Her right knee is contracted. She has congenital hip dysplasia (hip socket is not formed) resulting in her hip being dislocated. Denise had equinas valgus (foot that is turned outward) and had surgery to correct her feet so she could walk. After three miscarriages.

Spondyloepiphyseal Dysplasia Congenita (SED). This condition is inherited in an autosomal dominant pattern, which means only one copy of the gene is necessary to have this type of dwarfism. A person with this condition is of short stature (dwarfism). The name of the condition indicates that it affects the bones of the spine (spondylo-) and the ends of bones (epiphyses), and that it is present from birth (congenital). The signs and symptoms of spondyloepiphyseal dysplasia congenita are similar to, but milder than, the related skeletal disorders achondrogenesis, type II and hypochondroplasia.

Dorothy
Dorothy has SED. Her joints get tight and her muscles lack strength. Dorothy said, “My hips were not a problem during or after pregnancy. I had my first hip replacements
just a few years before I married, so they were in fine working condition up until 2001.” She had some balance and respiration problems in the last month of her pregnancy.

**Dystonia**

*Dystonia* is defined as “a syndrome of sustained muscle contractions, frequently causing twisting and repetitive movements, or abnormal postures.” There are various causes for dystonia, including hormonal abnormalities, brain injury, and genetic factors. Hereditary dystonia first becomes apparent when the affected person is between 5 and 15 years old.

**Dawn**

Dawn has a type of dystonia (similar to athetoid cerebral palsy) that is caused by damage to the basal ganglia in the brain. Her symptoms include involuntary twisting movements of the trunk. All four limbs are involved, and most of the time they are moving. Her speech is also affected. Dawn can walk short distances, but she uses a motorized wheelchair for long distances. Her disability also causes bladder and kidney problems.

**Fibromyalgia**

*Fibromyalgia* is a chronic condition characterized by fatigue and widespread pain in the muscles, ligaments, and tendons. Previously, this condition was known by other names such as fibrositis, chronic muscle pain syndrome, psychogenic rheumatism, and tension myalgias (2).

“Fibromyalgia is a noninflammatory syndrome characterized by complaints of widespread musculoskeletal pain for at least 3 months in absence of other conditions to account for the pain. The documentation of discrete tender points on physical examination is essential to making a diagnosis. Fatigue, headaches, and irritable bowel syndrome are other symptoms that are reported. Fibromyalgia is associated with increased psychological distress” (3).

**Felicia**

Felicia experienced pain in her shoulders, mid-back, elbows, hands, and knees because of her fibromyalgia. She was especially sensitive to pain and found that she was unable to handle normal amounts of pressure and was unable to have a massage. When Felicia had an exacerbation, her body ached as though she had the flu and she experienced extreme body pain. It took her several days to recover from any physical exertion such as a long hike or a long day at work. Felicia had been asymptomatic prior to getting pregnant. She had been unemployed for several months and, just before getting pregnant, she started a new, high pressure job. She was working 12 to 14 hours a day, 60 hours a week. Depression is a part of fibromyalgia and she was taking the antidepressant Celexa®, which is not harmful to the fetus. She was told to discontinue it and, as a result, Felicia became severely depressed. (See “Nadine Fiona” in Appendix A.)
HIP DYSPLEGIA

Formerly called congenital dislocation of the hip, this type of dysplegia involves a developmental abnormality of the hip that causes instability.

Hannah
Hannah’s pelvis is missing a hip socket. She has had bone grafts that failed, resulting in limited mobility. She has arthritis in her hip and spine.

Heather Ann
Heather Ann has hip dysplasia, scoliosis, and an amputation. Her acetabulum (a cup-shaped cavity in the pelvis that receives the head of the femur) and femoral head (the knob at the end of the thigh bone) never developed, so she has no hip joint. Her dysplasia may have caused her scoliosis. Her right leg did not develop normally and was amputated above the knee when she was 14 years old. Although Heather Ann has not been able to find a comfortable prosthesis and uses crutches, she moves quite skillfully. Heather Ann’s usual disability-related problems include muscle spasms in the stump, phantom pain when she is tired, and a constant, mild lower back ache.

CONGENITAL HIP DEFORMITY

Hilary
Hilary has proximal focal femoral deficiency, a congenital hip deformity in which the femur is short. This condition is caused in utero because of an inability to create bone. The clinical appearance is distinctive, with a very short thigh, flexed abducted and externally rotated hip and often flexion contracture of the knee. There may be associated fibular hemimelia. This condition has been classified into four sub-types according to the radiographic appearance (Aitken classification):

❖ Type A: Normal acetabulum with located femoral head, subtrochanteric femoral varus with pseudoarthrosis, which usually ossifies by skeletal maturity.
❖ Type B: Normal acetabulum and located femoral head. No osseous connection between the femoral head and shaft. The femoral shaft usually lies superior to the acetabulum and has a tufted proximal end.
❖ Type C: Dysplastic, flat acetabulum, absent femoral head, short femoral shaft with proximal tuft with no articulation between the femur and acetabulum.
❖ Type D: Dysplastic, flat acetabulum, absent femoral head, very short or absent femoral shaft with articulation between the femur and acetabulum.

The characteristics of this syndrome are malformation of the lower spine and short femoral (thigh) bones with missing knee joints. Hilary’s uterus is normal size, but it has two chambers. She has difficulty walking and uses artificial legs and Canadian crutches (also known as Lofstran™ crutches). The artificial legs are similar to stilts because she does not
have knees to bend. Moreover, she falls about once a month and has difficulty climbing stairs. Another disability-related problem is stress incontinence. Hilary used a wheelchair when she was pregnant with her second child. She started using the wheelchair full-time when her first baby was 1 1/2 years old, and she stopped using her artificial legs during the postpartum period.

**CONGENITAL HYDROCEPHALUS**

Congenital hydrocephalus is a condition in which there is too much cerebral spinal fluid on the baby’s brain because the fluid is unable to drain out. In technical terms, there is progressive ventricular enlargement noted either on fetal echo and/or apparent in the first days of life. It can be due to excessive formation of cerebrospinal fluid (CSF) (RARE - choroid plexus tumors), or decreased reabsorption of CSF or obstruction of CSF flow (4). There is obstruction of the normal flow of cerebrospinal fluid because of a blockage in the ventricles in the brain. This problem can be isolated or associated with spina bifida.

**Holly**

Holly has congenital hydrocephalus without any physical limitations. She has had nine shunt revisions. Her balance was only slightly affected during her first pregnancy, but the shunt had to be replaced 6 weeks after delivery. The probable cause was excess pressure put on the abdomen during the birthing process. Delivery of her first child was difficult because the fetus was large and lying in the posterior position. Her babies all lay on the right side of her uterus, which is near the distal end of her shunt, causing some discomfort. Her shunt tube drains into the peritoneal cavity.

**JUVENILE RHEUMATOID ARTHRITIS**

Other names for juvenile rheumatoid arthritis (JRA) include Still’s disease, juvenile chronic polyarthritis, and chronic childhood arthritis. JRA refers to a group of conditions that all involve inflammation of the joints, similar to adult-onset arthritis. About a quarter of a million children in the United States have JRA; most of them are girls. Joint inflammation in JRA often takes longer to lead to permanent damage than the inflammation of adult arthritis. The systemic symptoms of this condition include eye and skin problems. The exact combination of symptoms depends on the type of JRA an individual has.

**Jennifer**

Jennifer’s joints and skin are affected by JRA. Different joints are affected at different times; every joint is symptomatic at some time. The pain, swelling and limitation of range of motion she experiences are sometimes more severe. In addition, the skin over her whole body usually feels sore and sensitive. Her skin and joint symptoms are worse
when she is tired or weak. Jennifer’s ability to walk increased dramatically when she was pregnant.

**Joan**

Joan had bilateral hip replacements at age 13. She uses a motorized wheelchair. Joan’s arthritis affects all of her joints. During pregnancy, her arthritis went into remission and she did not feel the sharp grinding pain she usually experienced.

**Joy**

Joy’s joints are affected by JRA, but she walks all the time. She has limited movements in her wrists and one of her shoulders. She has had several joint replacements: her hips 11 years prior to her pregnancy and her knees 7 years prior to her pregnancy. Joy has experienced constant pain in her ankles as well as continued incontinence since her pregnancy.

**Julie**

Julie’s arthritis affects all of her joints. Her usual disability-related problems are difficulty walking and stiffness of the joints. Joint stiffness is especially severe in her ankles. Her disability affects her hands and knees. She usually uses a motorized wheelchair. Despite her joint discomfort, Julie commented that during pregnancy, “I felt better than some of my able-bodied friends did when they were pregnant.”

**Systemic Lupus Erythematosus**

Systemic lupus erythematosus (SLE), often referred to simply as lupus, is a disease resembling rheumatoid arthritis. It is an autoimmune disorder, which means that the immune system attacks other body tissues in a way similar to the way it attacks invading bacteria and viruses. SLE is a systemic disease that affects many organ systems.

Systemic lupus erythematosus causes a variety of symptoms and different combinations of symptoms. The most common problems are pain and swelling in the joints and kidney damage. Other problems include fever, fatigue, weakness, skin rashes, sensitivity to sunlight, headaches, and muscle aches. Seizures, personality changes, or emotional depression may result if the brain is affected. No cure has been found for SLE, but some of the symptoms may be controlled with proper treatment. Many people experience periodic remissions of symptoms.

**Laura**

Laura’s usual problems before pregnancy were aching joints, fatigue, high blood pressure, loss of vision in one eye (probably as a result of high blood pressure) and mental confusion. Laura had numerous problems during and after her pregnancy.
Lea Rae

Lea Rae has both SLE and rheumatoid arthritis. She has arthritis in all of her joints. She has had both hips and a knee replaced. In addition, she needed a hip revision in 1999. Lea Rae was especially tired during her pregnancy.

Leslie

Leslie’s SLE was not diagnosed until she had already had one premature baby and one miscarriage. She now realizes that she had experienced SLE symptoms for approximately 13 years before the disease was diagnosed. When working in hot weather that did not affect her co-workers, Leslie experienced severe rashes, vomiting, and hair loss. She had a constantly recurring streptococcal infection of the vagina and later realized that the infection kept recurring because her immune system was too weakened by SLE to resist infection. The effects of SLE on her pregnancies led to diagnosis of the disease. Since the time of the diagnosis, Leslie has had continuous problems with psoriasis. Her shoulders, hips, knees, feet, and hands have become arthritic.

Multiple Sclerosis

Multiple sclerosis (MS) is an adult onset condition with a variety of symptoms. There are four subtypes. Not only do people have different sets of symptoms, but one person’s symptoms will also vary over time. These variations are due to the nature of the condition. In medical terms, the symptoms of MS are caused by demyelination (loss of the myelin sheath that surrounds nerves). Myelin sheaths help with nerve conduction of the axon at various locations, followed by glial scar formation at some sites. Think of your nervous system as a set of telephone wires connecting a central switchboard (your brain) with the various parts of your body. With MS, the insulation of the wires wears away at various points, disrupting communications. If a worn patch is repaired, remission of symptoms will result, but demyelination (loss of insulation) of a different part of the nerve could cause the same symptom to reappear.

Multiple sclerosis most often first appears in individuals between the ages of 20 and 40 years. The symptoms of MS are so variable and confusing, however, that the disorder may not be diagnosed until years after the first symptoms appear. The cause of MS is not completely understood. It is an autoimmune disorder in which a person’s antibodies attack her own body tissues. The cause appears to be a combination of inherited and environmental factors. The reasons that the rate of progression varies among individuals are also not understood. There are medicines to slow the progression and treat some of the symptoms.

Mandy

Mandy was diagnosed with MS 6 months after the birth of her second child. Her first symptoms were double vision and numbness in her legs. Since diagnosis, Mandy’s common symptoms are fatigue, numbness, and depression.
Margie
Margie had been diagnosed with MS before she became pregnant. Her symptoms before pregnancy were weakness in the arm and leg on one side, and occasional bladder problems. Margie commented about her first pregnancy, “I felt great while I was pregnant! I enjoyed feeling so healthy and I had a positive outlook on life.”

Marsha
Before her pregnancy, Marsha walked with a limp and used a cane. Many years later, Marsha is still using only a cane.

Mary
Mary tired easily before her pregnancy. She could walk short distances unassisted, but she used a walker for longer distances, especially for getting up and down stairs. Her bladder control was slightly affected. After one miscarriage.

Michelle
Michelle’s MS symptoms were mild. The problems that led to her diagnosis were urgency and occasional incontinence, and blurred vision. Later, she had problems with muscle spasms and tired easily.

Mimi
Mimi was taking one of the drugs used to slow the progression of MS prior to pregnancy and “was happy to stop the drug” during pregnancy. She continued to feel well without it postpartum. Mimi walked with a wide gait prior to pregnancy and after delivery. Although she had more numbness on her left side, she felt better without medication. She had a grand mal seizure prior to delivery (she is unsure how many day(s) before delivery), but she had no seizure activity for 1 1/2 years after delivery. She felt dizzy and off-balance after her pregnancy. These symptoms could have been due to her seizure medication.

Moira
Moira’s main problem is fatigue. She is limited to walking no more than two blocks and uses a power wheelchair for longer distances. Prior to pregnancy she used Canadian (Lofstran™) crutches. Moira has used a cane when visiting friends since her pregnancy. She had intravenous immunoglobulin (IVIG) treatment 3 months in a row after giving birth. IVIG is “an immune system booster used to make sure I didn’t crash” during the hormone fluctuation from pregnancy to postpartum. Moira is “able to be alert, awake and take care of my child with this treatment and additional medication. I am taking my baby to swimming lessons.” She felt better after the pregnancy than she did before as well as during pregnancy, thanks to the IVIG.
Mona

Mona was put on oral baclofen while she was pregnant, but it was not successful and she was switched to tizanidine (Zanaflex®), which reduced her spasticity. Mona said, “I was told that there was no evidence of fetal abnormalities during pregnancy, but that the drug could be passed on in breast milk.” In spite of the success of the medication, she had difficulty writing because of tremors in her right hand. In addition, Mona had started to use a walker prior to pregnancy. She had an exacerbation of MS during her first trimester and lost strength in her legs. She also had numbness in her legs. By the end of the first trimester, she had more energy and her walking improved. Mona was encouraged to surgically implant the Baclofen Pump™, an alternative to tizanidine that requires much lower doses. In retrospect, Mona said, “If I could change anything about my baby’s birth, I would not have opted for the Baclofen Pump™. I wish I had not tried to breast-feed, but rather stayed on Zanaflex® and spent that time with my son. Also, I was given the choice in the hospital to not breast-feed and stay on the drug, or have the surgery and breast-feed. I let my mother convince me to have the surgery. My doctor left the decision up to me. I was hospitalized after the surgery for 2 weeks without my child and even though I used a breast pump, he basically was fed formula with some breast milk. He was not interested or accustomed to the breast, so after a very short stint of breast milk in bottles I gave up and fed him formula only. I don’t know if having two surgeries back to back was right for me, and the pump at that time may have been unnecessary.” Mona was prescribed a motorized wheelchair 6 months after her delivery and surgery for the pump. She used it when going outside for both a walk and shopping. Mona found the pump helpful.

Neuromuscular Disorders

“The broad category of neuromuscular disorders or diseases covers conditions that involve the weakness or wasting of the body muscles. Some of these conditions are covered by the Muscular Dystrophy Association, but they are not primary diseases of the muscles. These problems may arise in the spinal cord, the peripheral nerves, or the muscle fibers. Some may be hereditary, while others are acquired. Commonly recognized conditions fall into the categories of myopathies, which are diseases of the muscle such as muscular dystrophy; disorders of the junction where the nerve impulses are transmitted to the muscle such as myasthenia gravis; and neuropathies, which are diseases of the peripheral nervous system such as diabetic neuropathy” (6).

Charcot-Marie-Tooth

Charcot-Marie-Tooth is an unusual, slowly progressive form of muscular atrophy characterized by weakness and wasting of the feet and leg muscles followed by involvement of the hands.
Naomi

Naomi’s doctors are unsure of her diagnosis. The differential diagnosis is between distal spinal muscular atrophy and Charcot-Marie-Tooth. She uses leg braces. She used a walker during her first pregnancy and experienced carpal tunnel syndrome during both pregnancies. One of her feet became numb during her first delivery, but the numbness lasted only about 8 weeks. Naomi has since had a second child. She said, “The [second] pregnancy was worse, possibly because I was older. I was tired the whole way through and never really felt great like I had during the second trimester of the first pregnancy. I also got gestational diabetes in the third trimester and had to control my diet. In the second pregnancy the labor and delivery lasted only 1 hour and 15 minutes. Labor was about the same as before, but shorter. I knew the positions that worked for me and it went smoothly. Pushing was only a few minutes, which was a great relief. The first time it was 2 hours. Afterward they gave me Pitocin® for bleeding. Although my uterus was firm, I continued to bleed and got very dizzy. The doctor came back and removed many clots so my uterus could clamp down properly and stop the bleeding. My disability had nothing to do with these problems.”

Natalie

Natalie walks with two leg braces. She also has a weak grasp and needs two hands to pick up a glass. She described her hands as being “clawhands.” Natalie does not have any sensation in her hands or feet. She had difficulty climbing steps and lifting her legs into the car until 5 months post-delivery.

Nora

Nora uses a wheelchair and cannot use her fingers and toes. She could not transfer after the seventh month of her pregnancy. She felt weaker and had nosebleeds every night. Her physical condition after pregnancy returned to the same as before the pregnancy.

FRIEDREICH’S ATAXIA

Friedreich’s ataxia is an inherited, progressive disorder characterized by degeneration of portions of the brain and spinal cord. The disorder progresses slowly, usually causing death by age 30. The earliest manifestation is a wide-based gait—in which the feet slap the ground as they land—and difficulty sensing where the limbs are located in space. Scoliosis and clubfeet are also commonly associated with this disorder.

Noelle

Noelle had walked with the aid of Canadian (Lofstran™) crutches, but she started using a motorized wheelchair a month before she became pregnant. Her other disability-related problems included leg cramps, stress incontinence, back problems caused by
scoliosis, and some difficulty breathing. Her ataxia had progressed so much by 4 years after her pregnancy that Noelle could only stand with support for half a minute.

**Nikki**

Nikki had been walking with a walker but started using a wheelchair during her second pregnancy. She started using a motorized wheelchair in the beginning of her seventh pregnancy. Nikki does not have any difficulty with breathing except during her pregnancies. Her upper extremity ability is slightly affected. Her writing is wiggly now. In addition, reaching is getting hard. She can stand up leaning on the kitchen counter when she is not pregnant. Since her four early miscarriages.

**Limb-Girdle Dystrophy**

Limb-girdle dystrophy is a form of muscular dystrophy. “All limb-girdle muscular dystrophies (LGMD) show a similar distribution of muscle weakness, affecting both upper arms and legs. Frequently, the first reported symptoms will be difficulty climbing stairs, standing from a squatting position, or raising arms above the head” (7).

**Nadine Fiona**

Nadine Fiona is able to walk, but not up stairs. She has fibromyalgia that went into remission during the second trimester of pregnancy. Her balance got worse during pregnancy. She is also weak in her upper extremities, making it hard to place things in and out of the oven. Her back got weaker and stayed weaker, making it hard to go from sitting to standing. Nadine Fiona also has difficulty straightening up after she bends over at her waist.

**Natasha**

Natasha has limb-girdle muscular dystrophy and is unable to run. In addition, she has difficulty climbing stairs and bending over. Natasha started having problems getting up from a seated position prior to pregnancy. She has weakness in her arms and as a result she has difficulty lifting things. She has weak upper muscles, biceps, and pectorals. Her upper arm muscles, triceps, and deltoids, are good. Natasha felt stronger during her pregnancy because she was able to maintain a full schedule in spite of being pregnant.

**Nicole**

Nicole’s doctors are unsure of her diagnosis. Nicole was able to walk prior to her pregnancies, but she now uses a wheelchair. She cannot raise her arms over her head. Nicole has a grasp, but it is not strong enough to open tightly closed jars. She did not have any medical problems with any pregnancy except for transfers. Nicole has two children.
MYASTHENIA GRAVIS

Myasthenia gravis is an autoimmune disease that affects the transmission of signals from nerve to muscle. The onset is usually in women in their 20s and 30s. Myasthenia occurs when antibodies produced by the body’s immune system attack and destroy the acetylcholine receptor located at the muscle-nerve connection. People affected with myasthenia gravis experience weakness that worsens with activity and stress. Myasthenia gravis typically affects facial muscles and other skeletal or voluntary muscles. The eyelid muscles are the most commonly affected, usually causing the eyelids to droop. Sometimes chewing, swallowing, smiling, and talking are also affected.

Nadia

Nadia experienced myasthenia gravis symptoms during the second trimester of her third pregnancy, and could not hold onto a bottle or shampoo her hair. She was diagnosed with myasthenia gravis during the third trimester. Nadia had double vision 6 months after the birth of her child and weakness in her facial muscles as well as her arms and neck muscles. She did not have any problems with her legs until after the diagnosis was made. She was started on steroids the day after the baby was born. Nadia felt weak at the beginning of steroid treatment. She also had a thymectomy a month after her baby was born.

Noreen

Noreen was diagnosed with myasthenia gravis when she was 10 years old. Her disability symptoms vary from day to day, but her eyelids droop most of the time. Many mornings she has a hard time lifting her son.

SPINAL MUSCULAR ATROPHY

Spinal Muscular Atrophy (SMA) is a type of neuromuscular disorder. It is not one condition, but rather a group of eight similar conditions. All of the different types of SMA are genetically caused, but not all are familial, that is, a genetic disorder can result from a new mutation. Spinal muscular atrophies involve degeneration of neurons in the spinal cord, medulla, and midbrain. Dysfunction of these nerves leads to degeneration of the nerves in the muscles that, in turn, leads to muscle atrophy and progressive paralysis. Pulmonary function can also be affected. In some individuals, one set of opposing muscles is weakened more than the opposite set, causing scoliosis. The mode of inheritance, age of onset, severity, and progression of the condition vary among the different types of SMA. Infantile onset is Type 2, which is also known as Werdnig-Hoffman spinal muscular atrophy (disease).

Nancy

Nancy is able to move all parts of her body, although she has little strength in her limbs. She can move her arms more easily than her legs. Her condition has caused scol-
Nancy has broken her knees and each of her ankles on various occasions. Her inability to use her lower limbs has also contributed to osteoporosis (loss of calcium in the bone), which can lead to easy breaks in the bones.

**Nina**
Nina is from Sweden and received her medical care there. She is able to move all parts of her body, though she has little strength in her limbs. She can move her arms more easily than her legs. Nina has difficulty getting pregnant because she has irregular menstruation that has nothing to do with SMA.

**Osteogenesis Imperfecta**

Osteogenesis Imperfecta (OI) is an inherited disability that affects collagen, a major protein that forms connective tissue in the body. People with OI have less collagen and, therefore, their tissue is weaker than normal, thus causing weak bones. OI is an inherited disability, and a person with this condition has a 50 percent chance of having a baby with OI. There are four different types of OI, which vary in severity and characteristics. Most bone breaks occur before puberty. This is particularly true with Types 1 and 4. Type 1 is the mildest form and most of the fractures occur before puberty. Type 2 is the most severe form and only a few survive. Type 3 is the next most severe type and is associated with respiratory problems, bone deformity, loose joints, poor muscle development, and short stature. Type 4 is between Type 3 and 1 in severity. This type is associated with mild to moderate bone deformity, shorter than average stature, and barrel-shaped rib cage (8).

**Olivia**
Olivia does not know what type of OI she has. She has had more than 50 broken bones, mostly in the lower extremities. She found that pregnancy was good for her body.

**Oprah**
Oprah has had 300 to 400 breaks. She has Type 3 osteogenesis imperfecta. She started walking in her teen years and continued to walk throughout both pregnancies. During the third trimester of her first pregnancy, Oprah slipped on wet pavement and fell and broke her hip. She went into labor, but medication delayed labor and delivery by 10 days. Despite breaking her hip, her doctor could not believe how healthy she was. Oprah was also healthy during her second pregnancy. Only one of her children has OI. She has arthritis, 10 years later, and uses a manual wheelchair or crutches, depending on how she feels.

**Orielle**
Orielle has had around fifty broken bones. She has Type 4 osteogenesis imperfecta of moderate severity, and she uses a wheelchair.
POST-POLIO SYNDROME

Poliomyelitis is a viral illness that affects the anterior horn cells in the spinal cord. The anterior horn cell, or motor neuron, is the nerve cell that innervates the skeletal muscle fibers. Post-polio syndrome refers to problems that occur long after the viral infection has ended. When these nerve cells were destroyed, the muscles they served became weakened or paralyzed through lack of information being sent to the muscles, although sensation remains. Later in life, the overuse of the remaining nerve fibers begins to take its toll, and post-polio syndrome develops, often in individuals who had little outward signs of the original disease. Different muscles are affected in different individuals, depending on which nerves were damaged. One person may have difficulty breathing, whereas another may be unable to move her legs.

Although polio has been eradicated in the United States, it has not been in the rest of the world. Therefore, there are a number of women of childbearing age living in other countries—some of whom may have immigrated to the United States—who have post-polio syndrome.

Pam

Pam’s arms and hands were weakened by polio; she describes them as “60 percent functional.” She can write, cook, and hold a glass of water, but heavy tasks are difficult. Her legs are completely paralyzed and she uses a motorized wheelchair. Pam’s abdominal muscles are weak. In order to give her trunk enough support for sitting up, a muscle fascia was transplanted from her right thigh, with one end attached to her ribs and the other to her pelvis. Also, Pam’s left shoulder was surgically fused and she has a sway back. Pam had pulmonary function tests before she became pregnant and was assured that she would not have too much difficulty breathing.

Patricia

Patricia’s polio affects all four limbs and she has scoliosis. She can walk with the aid of braces and crutches, but usually prefers to use a wheelchair. Her arms are somewhat weak, but she is able to use them to propel a lightweight manual wheelchair. Patricia’s comment about her pregnancy was, “I had a better pregnancy than most of my able-bodied friends.”

Paula

Paula’s arms, legs, abdominal muscles, and back are all affected by post-polio syndrome. Her usual disability-related problems include difficulty in carrying large loads such as grocery bags, tiring easily, hip pain, poor circulation in the legs, and occasional muscle spasms. She walks with Canadian (Lofstran™) crutches. Paula contracted polio during her second pregnancy and the illness caused a miscarriage. She felt that, on the whole, her later, post-polio pregnancies were similar to the first.
Portia

Portia’s polio affected her legs, left arm and hand, neck, abdominal and low back muscles, and diaphragm. Her usual disability-related problems include occasional bladder infections, difficulty breathing, and coughing. Portia uses a wheelchair. Because she has had five children, with the last pregnancy occurring several years before her interview, she summarized her pregnancy symptoms as follows:

Portia contracted polio when she was 19 years old. She had her first child 2 years later. Her fifth child was born when she was 34 years old. Anemia was a problem during all her pregnancies. She also had morning sickness with all of her pregnancies and bladder infections during three pregnancies. Pregnancy also exacerbated her disability-related problems with constipation. Portia said that it was easier for her to cough when she was pregnant, explaining, “I didn’t need a corset when I was pregnant. The baby did the same job.” By the second trimester of each pregnancy, transferring became difficult. Portia was able to adapt, except that by the third trimester using a bathtub was impossible and she avoided going out alone. She said, “I stopped driving when I stopped fitting behind the steering wheel.”

Priscilla

Priscilla’s polio affected only her right leg. A muscle transplant was performed when she was 9 years old so she would be able to use the leg. When she was eleven, a pin was implanted in her left leg to slow its growth to a rate consistent with that of the right leg. Now, her right leg is somewhat thinner than her left and she walks with a slight limp. Before Priscilla’s first pregnancy, her right leg and hip often ached after she carried groceries up a steep hill to her house.

Rheumatoid Arthritis

There are a number of types of arthritis, all characterized by swelling, pain, and stiffness of the joints. Rheumatoid arthritis (RA), which affects about 1 percent of the population, is one of the more common forms of arthritis. People who have rheumatoid arthritis may experience other symptoms, including anemia, eye inflammation, and pleurisy (an inflammation of the membrane that surrounds and protects the lungs). Rheumatoid nodules occur in about 20 percent of rheumatoid arthritis patients in areas subject to pressure or trauma (often just under the skin), in the lungs, and in the heart. The causes of rheumatoid arthritis are still not completely understood, but inherited susceptibility, viral infection, and autoimmune response all seem to play roles in this disease. (Autoimmunity is also discussed in the section on systemic lupus erythematosus.)

Rachel

Rachel’s rheumatoid arthritis was diagnosed when she was a teenager. One of her shoulder joints was replaced during her late teen years. She has experienced intermittent flare-ups in her hands since her shoulder joint replacement. The aftereffects of the flare-
ups have left Rachel with weak hands. She did not have any pain or stiffness in her hands at the time of her first pregnancy. She had an exacerbation when her first child was 2 years old. She “woke up one morning with arthritis affecting every major joint” from her ankles to her neck. Since this flare-up, Rachel has had a hard time getting up from the couch as well as the toilet, getting into and out of the bathtub, walking, straightening her knees, and going up and down stairs. She has difficulty pushing and pulling, and washing her hair. She began her second pregnancy during this flare-up, which has been constant.

**Renee**

Renee’s rheumatoid arthritis was diagnosed when she was 6 months pregnant with her first child. Most of Renee’s symptoms were in remission between her first and second pregnancies. A month after the birth of her second child, Renee’s feet and hands were constantly painful. The pain and swelling in her hands was so severe that she could use them very little.

**Roberta**

Roberta’s usual disability-related symptoms before her pregnancy included aching and weakness in her hands, aching shoulders and knees, morning stiffness, and susceptibility to bladder infections.

**Sacral Agenesis**

Sacral agenesis is a term applied to a wide range of developmental conditions of the lower portions of the spinal column and pelvis. This term indicates that some portion of the lumbar spine, sacrum, or pelvis is incompletely or incorrectly formed at the time of birth.

**Sophia Amelia**

Sophia Amelia has sacral agenesis. She has no sacrum or coccyx (located at the end of the spine), and twelve vertebrae in her lower back are missing. Her nerves are composed of clusters of nerve endings, making her hypersensitive in certain places with no sensation in others. She has a dislocated pelvis that is also very small. She has partial arthrogryposis, resulting in skeletal and muscular deformities such as only one bone below the knee, floating kneecaps, and fixed or partially fused joints in her hips, knees, and ankles, with resulting degenerative arthritis. She can only put weight on one leg. When the spinal block for her second child was ineffective, the result was shooting pains in that leg which made it impossible to stand. This caused some difficulty with postpartum recovery and caring for herself and her newborn independently. She has partial arthrogryposis; her feet are fixed and she is unable to flex her feet. She has only one leg bone below her one knee.
Sophia Amelia has a neurogenic (spastic) bladder and only one functioning kidney, resulting in frequent kidney and bladder infections. She also has both an artificial bladder and sphincter. Sophia Amelia developed a seizure disorder between her first and second pregnancies. She noticed an increase in seizure activity during her first trimester, which she speculated was due to hormonal changes. She uses a manual wheelchair as well as crutches for short distances. Sophia Amelia used her crutches for a short time during the first trimester. She generally did not use her crutches during her pregnancies, due to changes in her center of gravity that caused problems with balance. She felt more stable using a wheelchair. Sophia Amelia had postoperative complications after both deliveries. Her digestive system had shut down and an NG tube (nasogastric) was inserted. This may have been caused by general anesthesia.

**SPINA BIFIDA**

Spina bifida is a deformity of the spine that occurs early in embryonic development. There is definitely a genetic component to some cases of spina bifida as well as an interaction between genetic and in-utero environmental factors.

The spinal cord contains a bundle of nerves that is surrounded by a protective covering called the meningeal membrane. The spinal cord passes through a column of ring-shaped bones, the vertebrae, which are separated and cushioned by discs of cartilage. The cord occupies the space inside the spinal, or vertebral, column. Spina bifida results from a failure of the canal to close properly. Other problems, such as clubfeet, may be associated with this defect.

There are three types of spina bifida, differentiated by the severity of the defect. The opening does not extend to the surface of the body in spina bifida occulta (occulta means “hidden”). The problem is in the vertebrae. Sometimes there are visible changes in the tissues overlying the defect; sometimes it is found by palpation or by X-ray examination. Spina bifida occulta usually occurs in the lower spine and is occasionally accompanied by scoliosis or problems of the feet. Symptoms will depend on the extent of the lesions. It can be very mild, and in some individuals the only symptoms may be backaches. Others may have more severe symptoms such as atrophied leg muscles, bowel and bladder disorders, or sensory loss.

More severe types of spina bifida are meningocele and meningomyelocele. In meningocele, some of the meningeal membrane protrudes through the hole in the vertebra to the surface of the body. In meningomyelocele, the nerve roots and spinal cord are attached to the wall of the meningeal sac. As with spinal cord injury, symptoms depend on the location and extent of the lesion.

**Sabine**

Sabine has the myelomeningocele form of spina bifida (a small protrusion that was not open to the skin of a portion of cord and membranes; a hairy spot designated the site (hairy nevus). She also has scoliosis and no sensation in her right foot.
Sabine had surgery to provide bladder control during which the ureters (tubes connecting the kidneys to the bladder) were attached to the segments of ileum (last segment of small intestine) so that her urine drains into the ileum and then into a bag attached to the skin rather than the bladder. She had this procedure done many years prior to her first pregnancy and it needed to be redone after her second.

Although Sabine has had radicular pain (pain due to disease of the spinal nerve roots) her whole life from unknown causes, she experienced an increase in pain during the fifth month of her first pregnancy. A possible explanation may be that a nerve root was pinched, causing an increase in pain. Her pain started soon after amniocentesis. The natural loosening of the joints and the swelling that accompanies pregnancy could have worsened the pain. Moreover, Sabine had surgery to remove her gallstones during this time. This may also have contributed to the radicular pain. Her radicular pain follows the trail of a particular nerve that is being pinched. She had the nerves cut, but this did not stop the pain. Since cutting the nerves was ineffective, Sabine tried medication, which she has found to be effective in controlling her pain.

Sabine’s anal sphincter muscle is weak so she takes Lomotil® to keep her bowel movements firm. This required an adjustment in her medication during pregnancy.

Sasha
Sasha had meningocele and two clubfeet. She was able to walk with the aid of Canadian (Lofstran™) crutches. She has used a manual wheelchair more as she has grown older. Her bladder control was poor and she had frequent infections of the bladder and kidneys. Her usual problems included edema and muscle spasms in her legs. Her feet were free of pressure sores only when she was pregnant.

Sherry Adele
Sherry Adele had the myelomeningocele form of spina bifida (an open protrusion of the cord and membranes) at L5-S2, but she has an incomplete lesion. She was born with two clubfeet and some hammertoes. She had one foot amputated and uses a prosthesis. She is able to walk without assistive devices, although both of her legs have diminished sensation. Moreover, she has a spastic neurogenic bowel, and is unable to urinate without using a catheter. She had been doing self-catherization for 10 years prior to her pregnancies. Sherry Adele had many surgeries as a child; some of which may have been experimental. She had surgery to enlarge her urethra then, years later, another surgery to decrease the size of her urethra. Sherry Adele thought that the doctors did not know how to manage her bladder problems. She has had many bladder infections. Her bladder is both hypertonic and hyperactive.

Sienna
Sienna uses both a power and a manual wheelchair and occasionally walks with crutches. She has limited sensation below her waist in both legs and sometimes experiences spasticity in her legs (a condition described by stiff or rigid muscles). Sienna is not
aware of any reason why this occurs. She has some sensation in her bladder and a full sensation in her bowels. Sienna does self-catheterization. She gave birth by caesarean section after having three miscarriages.

Sierra
Sierra walks with Canadian (Lofstran™) crutches, but she is unable to bear weight on one of her legs. She has limited sensation below the waist and in both legs. Spasticity in her legs occurs infrequently for no apparent reasons. Her bowel and bladder are not affected. Sierra’s child has mild cerebral palsy, cause unknown.

Simi
Simi has the myelomeningocele form of spina bifida (an open protrusion of the cord and membranes at L5-S2). She uses short leg braces and had edema during pregnancy. She also had poor bladder and bowel control. She was constipated during her pregnancy, but has not had any bladder infections since she was 19 years old. Her bladder was numb for a year after the delivery.

Sybil
Sybil has meningocele and arthritis of the spine. The arthritis causes backaches in cold weather. Sybil can walk with crutches, but she has no sensation in her legs. She often gets pressure sores on her legs, and muscle spasms are also a problem. She had a urostomy, an operation in which the ureters (the tubes leading from the kidney to the bladder) are detached from the bladder and brought to the surface of the skin. The urine then drains into a collecting bag. Her bowel control is also poor.

Spinal Cord Injuries
This type of irreversible damage to the spinal cord typically results from injuries that might be sustained as the result of a driving or diving accident, a gunshot wound, or a fall. The damage can cause loss of movement or loss of sensation, or both.

The spinal cord carries messages between the brain and the rest of the body, in much the same way that a telephone line carries messages between a central switchboard and individual telephones. If a storm occurs, damaging several wires in the cable, not all the houses will lose telephone service, but only those connected to the damaged wires. Similarly, the particular disabilities that a person experiences will depend on which nerves in the spinal cord bundle were damaged. The level, or area, of the spinal cord that is damaged—and the extent of that damage—is significant in determining the type of disability. The level of injury is defined by referring to the vertebrae closest to the injury site. Starting from the top, the neck vertebrae are numbered C-1 to C-7; the vertebrae in the upper and mid-back are numbered T-1 to T-12; and the vertebrae in the lower back are numbered L-1 to L-5.
All four limbs will be affected if the spinal cord injury occurs in the neck. This condition is called quadriplegia. Injuries closer to the skull cause high quadriplegia. Injuries above the C-3 vertebra are almost always fatal due to a loss of innervation to the muscles that control breathing; injuries at C-3 are often fatal; injuries from C-3 to C-5 cause quadriplegia; and people who have spinal cord injury from C-5 to C-7 have some limited hand use. Injury to the thoracic spine level 8 (the part of the spine behind the breastbone) causes paraplegia (affecting the lower limbs) in which trunk control is affected. Injury to the lumbar (low back) spine causes paraplegia. The muscles in the limbs are not the only ones affected. Spinal cord injury affects the abdominal muscles and some of the back muscles. Bowel and bladder control are also affected to varying degrees. Generally people with quadriplegia have difficulty coughing and may have other breathing difficulties.

Women whose injuries are above T-6 (sometimes to T-8) experience autonomic dysreflexia, also called hyperreflexia. Dysreflexia results from the uncontrolled release of norepinephrine, which causes a rapid rise in blood pressure and a slowing of the heart rate. These symptoms are accompanied by throbbing headache, nausea, anxiety, sweating, and goose bumps below the level of the injury (9).

Sometimes a person may experience nasal stuffiness and changes in heart rhythm. On any one occasion an individual might experience a combination of many possible symptoms. A common term for episodes involving relatively mild symptoms is known as quad sweats. Dysreflexia can be stimulated by ordinary events such as bladder fullness or the insertion of a speculum during a pelvic examination. Symptoms may resolve by removal of the stimulus. For example, by emptying the bladder or removing the speculum.

Although most of the interviewees did not feel labor contractions, most were able to feel fetal movement.

**Sally**

Sally is a quadriplegic whose level of injury is at C-5/6. She has limited use of all her limbs. She can lift her arms and has some use of her hands and wrists. Sally cannot use her fingers but can lift her wrists. She can stand with support by using her spasticity, and she can do a pivot transfer with support. Her spasticity diminished by the second trimester, which prevented her from assisting with transfers. She frequently has bladder infections.

**Samantha**

Samantha is paraplegic with an injury at T-10/11/12. She was injured after she had already had two children. Her third child was born 10 years after her injury. Her legs are paralyzed and there is some calcification in her hips. She has a suprapubic catheter, a catheter that is inserted into the bladder above the pubic bone. Samantha felt that her last pregnancy was much the same as her first two, with the exception of specific disability problems such as trouble transferring. She remarked, “It wasn’t as bad as I thought it would be.”
Shanna
Shanna has a spinal cord injury at T-11. She had surgery a year before her pregnancy to implant a Neuro-Control™ device to control bladder problems. Soon after the delivery, however, it needed to be removed due to bladder infections. It is unknown why the device was dislodged. (This problem is rare.) Shanna had a second pregnancy without the device and had no bladder infection. She was on bed rest in her third trimester because of early labor pains.

Sharon
Sharon’s injury occurred at the T-6 level. Her legs, feet, lower abdominal muscles, and some low back muscles are paralyzed. She had phlebitis (inflammation of a vein) in one leg just after she was injured. Another problem is occasional muscle spasms. Because of difficulty with self catheterization during pregnancy, she used an indwelling catheter. After delivery Sharon was unable to resume self catheterization because her bladder had lost elasticity.

Sheila
Sheila is a quadriplegic whose level of injury is at C-5/6. She has limited use of all limbs. She can lift her arms, has some use of her hands, can stand with support, and can do a pivot transfer with support. Her bladder tends to retain urine, but she knows when she has to urinate because she starts to sweat (a dysreflexia symptom). She has problems with dysreflexia and constipation when she is under stress.

Shelby
Shelby is a quadriplegic whose level of injury is at C-7/8. She has use of her arms and good hand grasp. She was able to transfer throughout her pregnancy. She had continual bladder infections. She experienced dysreflexia during her eighth and ninth month of pregnancy.

Signey
Signey had a spinal cord injury when she was 19 years old that resulted in quadripare-sis, meaning she is not paralyzed and is able to walk. Although she has limited use of her right hand, she can write with it as well as type with one finger. Her fingertips and toes feel somewhat numb. Signey has had bladder control since rehabilitation. She used enemas to manage her bowels prior to pregnancy and through the first trimester.

Sonya
Sonya has a spinal cord injury at C-3/4. She has a Baclofen Pump™ to reduce her spasticity. This device helped reduce her muscle spasms before and after pregnancy, but not during her pregnancy. It might not have worked, because the dosage was not increased even though it is safe to do so. Her paralysis is from the neck down. She does intermittent catheterization. Sonya uses a reclining wheelchair.
Stacy
Stacy’s injury was at the C5/6 level. She has some use of her hands. She uses a walker for short distances and a manual wheelchair for long distances. Her usual problems include scoliosis, an inability to sit up without support from a girdle, dysreflexia when she needs to urinate, and occasional light-headedness.

Stephanie
Stephanie has an injury at the T-12 level. She has some sensation in the right hip. She has some internal sensation in her lower abdomen and feels bladder fullness, but needs to use a catheter. She has problems with edema. She sometimes walks with the help of braces and crutches. Stephanie’s comment about her pregnancy was, “It didn’t seem that different from other people. My cousin has a heart-shaped uterus, too, and she had the same problems as I did.”

Sydney
Sydney has a spinal cord injury at T-4/5. She did not feel her baby move unless she had her hands on her belly, which could have been the result of where the placenta was implanted in the uterus. She did feel her baby when he kicked her in the ribs. She had difficulty pushing her wheelchair up an incline while pregnant. She has sensation above the right nipple and below her left nipple. Sydney was able to nurse only from her left breast.

Sylvia
Sylvia is a high quadriplegic, with injury at C-3/4/5. Her whole body is affected from the neck and shoulders down. Her bowels often retain feces, and she has no bladder control. She sometimes has muscle spasms so strong that her body thrashes about. She has occasional episodes of dysreflexia, and often has fainting spells just before menstruating. Sylvia’s baby was delivered vaginally using forceps because the baby’s shoulder was caught in the birth canal.

Spinal Tumor
Spinal cord tumors are abnormal growths of tissue found inside the bony spinal column. Benign tumors are non-cancerous, and malignant tumors are cancerous. Most primary tumors are caused by out-of-control cell growth. The cause of most primary tumors remains a mystery. They are not contagious and not preventable. Spinal cord tumor symptoms include pain, sensory changes, and motor problems. The three most commonly used treatments are surgery, radiation, and chemotherapy. All of the interviewees had surgery.

Selina Tracy
Selina Tracy had a tumor at the thoracic level (T4) and has been disabled since the age of two. She has full use of her hands and partial use of her trunk. She does intermittent
catherization. When she was not pregnant, Selina Tracy only experienced a bladder infection periodically. She uses a manual wheelchair and experiences carpal tunnel. She also has a diagnosis of thoracic outlet syndrome.

**Sara**
Sara had a spinal tumor removed when she was a child and is now paraplegic. She has some sensation and movement in her left leg but none in her right; she uses crutches. She has never had pressure sores but does have problems with muscle spasms. She has scoliosis and frequent backaches. Her other problems are frequent constipation, susceptibility to bladder infections, and frequent urination.

**Thoracic Outlet Syndrome**
The simple definition of thoracic outlet syndrome (TOS) is that this condition includes neurovascular symptoms in the upper extremities due to pressure on the nerves and vessels in the thoracic outlet area. The specific structures compressed are usually the nerves of the brachial plexus and occasionally the subclavian artery or subclavian vein. The symptoms are produced by a positional, intermittent compression. Thoracic outlet syndrome is a group of symptoms arising not only from the upper extremity, but also in the chest, neck, shoulders, and head. The diagnosis is made easier by the physician’s awareness and with physical examination using certain criteria, including elevation of the hands, suprACLavicular tenderness, and weakening of the 4th and 5th fingers (10).

**Taryn Dion**
Taryn Dion has both TOS and degenerative disc disease. The degenerative disc disease affects her 4th and 5th cervical vertebrae, causing pain in both of her arms, hands, shoulders, chest, upper back, and the lateral vertebral muscles that attach to the ribs and go up the side of the neck (scalene muscles). Her pain varies and generally worsens with use. One of the causes is constricted venous return from the arm and hands, which has resulted in a chronic inflammation in all of her upper extremity muscles as well as direct compression of the brachial plexus nerves. She had a breast reduction 15 years prior to her pregnancy.

**Tessa**
Tessa has TOS bilaterally (on both sides) due to constriction under her collarbone. Her first symptoms of TOS started in her 20s. Tessa has 60 percent use of her left arm and 75 percent of her right. She uses her left arm for strength, endurance, and coordination. Although her right side is dominant, she experiences chronic pain in her right shoulder and neck.

**Tina**
Tina has pain in her upper and lower back, neck, left shoulder, and both arms. The pain in her left hand and left side are worse due to swelling on that side. She also has
intermittent numbness in her shoulder. She had a hard labor and was given morphine. The medication altered her perception of pain, which resulted in Tina’s clutching the bed bar with her hands. This strenuous activity caused an exacerbation that lasted 6 weeks. Since then, Tina has been in remission with guarded activity.

**Closing Comments**

Pregnancy is an enterprise of uncertainty and hope, and although no one can guarantee an ideal experience, the most important advice from these women is: “Enjoy yourself!”