

Caring
for
& Infants
& Children
with
Osteogenesis
Imperfecta



A Companion
Guide to the Video
You Are Not Alone
From the
OI Foundation



Osteogenesis Imperfecta Foundation

804 West Diamond Ave., Suite 210

Gaithersburg, MD 20878

(800) 981-BONE or (301) 947-0083

Fax: (301) 947-0456

www.oif.org E-mail: bonelink@oif.org

The mission of the Osteogenesis Imperfecta Foundation, Inc., is to improve the quality of life for individuals affected by OI, through education, awareness, mutual support, and research to find a cure.

National Institute of Health Osteoporosis and Related Bone Diseases~National Resource Center

1232 22nd St. N.W.

Washington, DC 20037-1292

(800) 624-BONE or (202) 223-0344

Fax: (202) 223-2237 TTY: (202) 466-4315

www.osteoporosis.gov E-mail: orbdnrc@nof.gov

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The information and guidelines provided in this pamphlet have been gathered from parents who have dealt with the problems unique to children with osteogenesis imperfecta (OI). While this information has proven helpful to other parents, it is in no way recommended for every child in every situation. Please consult with your physician concerning all phases of health care for your child. The Osteogenesis Imperfecta Foundation, Inc. (OIF) is not responsible for any damages or personal injury due to individual use of the suggestions contained herein.

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What is Osteogenesis Imperfecta?

Osteogenesis imperfecta (OI) can literally be translated as “imperfectly formed bones.” Most forms of OI are caused by imperfectly formed bone collagen that results from a genetic defect.

Collagen is the major protein of the body’s connective tissue and is the framework upon which bone and tissue are built. It can be likened to the framework around which a building is constructed. If the collagen framework is defective, the bones fracture easily, the skin is loose and transparent, and the muscles lack tone. People with OI either have less collagen than normal or a poorer quality of collagen.

There are at least four types of OI, known as types I, II, III and IV. It is believed that there are between 20,000 and 40,000 people with OI in the United States. The disorder also affects people in other countries throughout the world.

Characteristic Features

OI varies significantly according to type, and it is very difficult to predict what symptoms or complications your child will have. Please keep in mind that very few people with OI exhibit all of the following symptoms, and that the severity of each symptom can vary tremendously between individuals. Common features include:

- Bones that fracture easily
- Short stature
- Hearing loss
- Discolored, brittle teeth
- Blue sclera (blue color in the whites of the eyes)
- Skeletal deformities of limbs, chest, and skull
- Scoliosis (curvature of the spine)
- Respiratory difficulties
- Weak muscles
- Excessive sweating
- Constipation
- Tendency to bruise easily
- Loose joints and ligaments
- High-pitched voice



Genetics

It is important for you to understand that nothing you or your spouse did during conception or pregnancy caused this condition in your child. OI has been prevalent for thousands of years. Genetic counseling, which is available at most hospitals, may help you understand the type of OI your child has. If you are thinking about having more children, you should consider contacting a geneticist who can help determine the probability of recurrence of OI in your family.

Learning That Your Child Has OI

If there is a previous history of OI in either the mother's or the father's family, you probably have some idea what to expect and how to manage the disease. You should be aware, however, that a child's symptoms and severity may differ from those of the parent with OI; that is, the child may not necessarily be affected in the same way that the father or mother was.

When you are not expecting your child to be born with a disability, it can be a terrible shock and may be very upsetting. Having a child with a disability such as OI can be very trying, and may not be something that you thought could ever happen. Don't be ashamed to cry or express your disappointment to friends and loved ones. As with any grieving process, you will most likely find yourself repeatedly going through stages, such as refusal to believe there is a problem, anger or looking for someone to blame, depression, and finally, acceptance. There are many excellent books available that deal with the birth of a child with a disability that you may find helpful (see the Additional Readings section at the end of this publication).

Most psychiatrists agree that parents of children with disabilities will benefit from joining with other parents whose children have similar problems. Our hope at the Osteogenesis Imperfecta Foundation is that we will be able to provide you with not only information, but also a support network of others who are grappling with, or have solved, some of the same issues that you will be facing.

If you have not already done so, you will need to contact a pediatrician and an orthopedic surgeon. It will be worthwhile to find doctors whom you trust and with whom you will be able to work closely, preferably those with experience treating patients with OI. The OI Foundation's physician referral list is available to assist you with

locating a doctor. Many OI families find that their doctors become like members of the family. Eventually, you may find it necessary to take your child to a physiatrist (a habilitation and rehabilitation specialist). Physical and occupational therapists can help your child develop muscle tone, strength, and cognitive skills. Social workers who work with children with disabilities may also be helpful with family and marital difficulties should they arise.



It would be wise to evaluate your health insurance coverage. OI can become very expensive, and the financial strain can often become as burdensome to a family as the health problems. There are many organizations and clinics that help with some of the costs associated with birth defects. One organization is the Shriners Hospitals for Children; these hospitals provide free medical services to those who qualify. Medical services vary greatly from state to state; check with your local and state governments to determine what is available in your area.

One note of caution: Because awareness about child abuse is rising, it is not uncommon for parents of children with OI to be mistakenly suspected of this crime. When you find it necessary to seek medical help away from your regular doctor, be prepared to answer questions about your child's condition calmly and with understanding. A physician's primary concern is usually the overall welfare of the child, and knowledge of OI is not as widespread as we all would like it to be. It is a good idea to carry a letter from your doctor with you at all times stating that your child has a diagnosis of OI and explaining what that means. Many parents also carry a copy of this letter in the glove compartment of the car. When you travel, carrying copies of your child's medical records can alleviate many potential problems.

Taking Care of a Child with OI

In most ways, caring for the child with OI is just like caring for any child. There are, however, a few precautions and tips unique to handling babies with OI that we would like to share with you.

Car Seat and Strollers

You will need a car seat to take your baby home from the hospital. Look for an infant seat that reclines as much as possible, and give careful consideration to how easily the child can be placed into or removed from the seat. You may want to pad the seat with egg crate foam (available from medical supply stores), or one-inch foam (available from fabric stores). In addition to lining the bottom of the seat, place a layer of foam between the harnesses and the child for extra protection.

As with any child, it is important that the child with OI be safely confined in an approved car seat placed in the back seat. For maximum safety, **never** place an infant or child car seat in the front passenger seat, because airbags can be dangerous, especially for children with OI.

Snug Seat® manufactures an excellent car seat for toddlers with OI for when your child is able to sit up. The seat is adjustable to accommodate the child when he or she is in a spica cast (a cast that goes up over the child's hip).

As with your car seat, you will need a stroller that reclines considerably and is wide enough to accommodate casts. Fisher Price® manufactures a three-wheeled stroller that many parents have used successfully. Sling or umbrella-type strollers are unsuitable because they lack leg support and do not provide good positioning of the spine and head.

Handling

Common sense is the best guide when handling a child with OI. Remember that the bones are very fragile and can break with little or no pressure. Be especially careful of the long bones in the body, i.e., the arms, legs, and ribs. You should not lift your baby under the armpits or pull on his or her arms or legs. When you change diapers, lift the baby by the buttocks, not by the ankles as is customarily done. Spread your fingers apart as far as possible, and put your hand under the buttocks with your forearm under the baby's legs to prevent them from dangling. To lift the baby onto your shoulder or carry the baby, use the same technique, but with one hand placed behind the head and the other behind the buttocks, again with fingers spread as far as possible. When lifting or moving your child, be careful that little fingers and toes do not get caught on the clothing you are wearing, such as shirts or blouses that button down the front. Many parents find it helpful to insert a piece of egg crate foam rubber or a thick piece of foam rubber into a pillow-

case, and to use this aid to transport the baby. Some parents use a pillow. This type of support can also be used as a base when holding the baby.

When a child has a painful fracture, it is usually best to avoid lifting or moving him or her as much as possible. After some degree of healing occurs, the fracture will be less painful, and moving your child will be easier. Unfortunately, leaving your child in one position for a long time can cause skin rashes and sores. Putting a child in different positions not only prevents these problems, but also helps the child develop different sets of muscles, which is important for later mobility. Some parents have found the following method for shifting a baby from its stomach to its back (or vice versa) to be useful when conventional methods cause discomfort:

This procedure is best accomplished by two people. Position the baby on his or her back on a pillow or a covered piece of foam rubber. Turn the baby's head to one side. Then place a second pillow or piece of foam on top of the baby, sandwiching the child. Position one person at the baby's head and the other person at the feet. Each person places one hand under the bottom pillow and the other hand on top of the upper pillow, and at the count of three, the child is flipped onto his or her tummy. Be sure both participants agree beforehand on the direction that the baby will be turned. This method, although a little awkward, provides a way to change the baby's position without causing unnecessary discomfort.

When lifting your child, remember to use good body mechanics to prevent back injury to yourself. Always have the child as close to you as possible before beginning to lift. Flex your knees slightly and lift with your legs instead of your back.

Do not be afraid to show affection to your child by cuddling, rocking, touching, and talking to him or her. Frequent stimulation is necessary for sound emotional and social development.

Clothing

Children with OI are frequently affected by warm temperatures and are often bothered by excessive sweating. Lightweight, cotton clothing seems to be the most comfortable. Look for clothes with buttons or snaps down the front and at the crotch. Many parents

fashion “cast underwear” by placing snaps or Velcro at the crotch of their child’s underwear to simplify toileting.

Children with OI generally do not outgrow their clothes as quickly as other children, however many parents feel that it helps to increase their child’s self esteem to invest in current styles and fashions. Developing a positive self-image in a child with OI is sufficiently difficult without having the child feel self-conscious about his or her clothes.

Bathing

Most babies enjoy bath time, and bathing can also be one of your child’s favorite activities. Before your child is able to sit unaided, you will probably find it helpful to purchase a molded sponge bathing aid to lay in the bottom of the tub. A popular variety is the kind with the baby-shaped cutout. When sitting is feasible, there is a helpful aid called a “safety bath ring,” a circular ring with suction cups that attach to the bathtub floor.

It is possible to bathe a baby who is wearing a sling for a fractured arm. Simply leave the sling on during the bath, and replace it with a dry sling after taking the baby out of the tub.

Babies who are wearing a cast must have sponge-baths. Be very careful not to get the cast wet. Washing hair is most easily accomplished by placing the baby on the counter top next to the sink and supporting the baby’s head over the sink. You can then spray or pour water to wash the hair.

Recognizing Fractures

Dealing with fractures will be very difficult for you. Nothing pulls harder at a parent’s heart than to repeatedly witness your child experiencing the pain of a fractured bone. Try to remain calm and comfort your child the best you can.

How does one know when a baby with OI has a fracture? In most instances, your child will cry out suddenly and loudly. Sometimes you might actually hear the snap of the bone. If you suspect a fracture, first try to calm your child. When the crying has stopped, very slowly and carefully experiment by gently touching or barely lifting each limb. You can usually pinpoint the fracture fairly accurately. When you lift or move the fractured bone even slightly, your child will wince or cry out. This reaction will help you determine where the fracture has occurred.

Be especially careful to immobilize this bone as much as possible when moving your child.

There are different types of fractures; some are extremely painful, while others are more tolerable. With fractures of the arm, many children hold the sore arm against their bodies in an effort to self-splint it. With some fractures, you might notice swelling or bruising of the area or warmth of the skin around the area.

What to Do When a Fracture Occurs

First, do not blame yourself, your spouse, or whoever was with your child when the fracture occurred. The sooner you can accept fractures as a part of your child's physical makeup, and not as the world's greatest crisis, the better off you will all be. Fractures will occur no matter how careful you are. Sometimes you might be shocked that a bone doesn't break when you thought that a fracture was inevitable. Any adult who has lived a lifetime with OI will tell you that it is much better to live life to its fullest, take a few risks, and possibly suffer some fractures, than to exist in a padded world trying to avoid broken bones.

At first, you will want to take your baby to the orthopedic surgeon whenever a fracture occurs. As you become more familiar with your child's condition, the physician may suggest that you care for the fracture at home.

To ease the initial discomfort after a bone fractures, you can administer pain medicine as prescribed by your physician. Then carefully transport your child to the doctor. If it is very uncomfortable for your baby to be moved, consider devising a stretcher out of a piece of plywood padded with foam or a pillow. Drive slowly to avoid potholes and jarring.

Fractures are usually treated by applying a cast. Many doctors choose to cast only fractures that are causing a great deal of discomfort for the child or that need the immobilization that a cast provides to ensure proper healing. There is a concern that application of a cast causes decreased mobility and increases the likelihood of osteoporosis (or increased bone brittleness). This can lead to even more fractures and cause the bone to become more brittle. For this reason, many physicians limit casting for children with OI as much as possible. They may apply a splint and wrap the area with an elastic bandage.

The type of cast most frequently applied to the legs is called a hip

spica cast. This type of cast is applied around the waist and over one or both legs, leaving the crotch area exposed. Since this type of cast makes toileting or diapering very uncomfortable for the child, some parents choose to gently slide a thin, absorbent hospital pad under the child and remove it as it gets soiled.

Arms are cast less frequently than legs in young children because the weight of the cast causes difficulty, and the bone near the armpit could receive too much stress from the movement and weight of the cast. Often, the doctor will simply apply a sling to a fractured arm, wrapping it firmly against the body for support. When this type of sling is used, watch for color changes that may indicate problems with circulation.

If you decide that you want to observe your child before going to the doctor, or if you have some distance to travel before you can obtain medical help, you may splint a fractured bone as follows:

Femur (thigh bone): There are two methods that parents have found to be effective:

1. A broken leg can often be protected (especially for sleeping) by simply placing a small folded hand towel between the child's legs and wrapping both legs together with an elastic Ace bandage. The towel will prevent chafing and will lend some rigidity to the legs.
2. Cut an oval piece of cardboard that is 4 to 5 inches wide and as long as the child's thigh from hip to knee (or from hip to ankle). Bend it to curve around the leg, cupping the bone like a cast. Pad the cardboard with soft fabric or a blanket. Wrap an elastic Ace bandage around the cardboard brace. Wrapping is most easily accomplished by two people, one of whom wraps and one of whom holds the leg. When wrapping with an Ace bandage, roll the bandage on without stretching it to allow for swelling. Leave the toes exposed and frequently check for color changes that indicate lack of circulation. Watch also for any swelling and color changes in the splinted limb. A deep pink or red color indicates that the splint is too tight and an adjustment must be made.

Humerus (upper arm bone): Support the arm as firmly as possible against the body, limiting motion as much possible. For an effective temporary sling, simply pin the sleeve of a long-sleeved shirt to the shirt body above and below the wrist and at the elbow.

Radius and ulna (lower arm): Pad a magazine with a small towel, wrap it around the arm, and secure it with an Ace bandage.

Cast Care

Casts are usually made out of plaster or fiberglass. Some physicians prefer plaster because it is easier to mold to the limb. Fiberglass dries more quickly and is not as easy to mold, but is lighter in weight and less susceptible to crumbling from moisture. Some general precautions include the following:

1. Follow your doctor's instructions carefully regarding physical activities.
2. Move fingers or toes frequently to reduce swelling and prevent joint stiffness.
3. Never get the cast wet.
4. Keep dirt, sand, powders, and lotions away from inside of the cast, and do not pull out the cast padding.
5. Don't use objects to scratch underneath the cast. You can cause serious skin damage, and objects lost beneath the cast can lead to pressure sores, abrasions, or even infections.
6. Do not break off rough edges or trim the cast. Contact the doctor to have rough edges repaired.
7. Don't ever attempt to remove the cast yourself. Your physician has special equipment for cast removal.

The most difficult problem faced by parents of young children with leg casts is urine seeping into the cast. Not only does the moisture cause the cast to crumble, but the odor can be very difficult to tolerate. No matter how hard you try, preventing the cast from retaining an odor is very difficult, and your whole family will be eager to have the cast removed when the time comes! The following is a list of ideas that other parents have found helpful:

- Disposable diapers can be folded down at the front and back edges approximately one inch and tucked under the inside edge of the cast.
- Plastic wrap can be tucked in around the edges of the cast in the pubic area.
- Be sure to change the diaper more often than you would otherwise.
- If the child is sleeping on his or her tummy and cannot turn over because of the cast, his or her buttocks can be left exposed for short periods of time to give the back of the cast a chance to dry.

Remember that as your baby grows, bladder and bowel management will become a much simpler routine.

X-rays

For most people with OI, x-rays are a frequent and necessary means of assisting with diagnosis and treatment. There are definite health hazards associated with exposure to x-rays, and these hazards are believed to have a direct relationship to the amount of radiation received.

Keep a precise record of your child's x-rays. Note the type, purpose, date, physician or dentist, and office or hospital where the x-rays were taken. Discuss your concerns with your physician and x-ray technician. Consider using any previously taken x-ray, and try to avoid retakes whenever possible. Sometimes a physician can utilize an unclear x-ray instead of taking a new one.

If a parent wants to assist in the x-ray room, he or she may need to insist. You know better than anyone how to handle your child. Some technicians do not fully understand OI, and you might find it necessary to diplomatically instruct them. Always ask for a lead apron for yourself and a lead shield for your child's reproductive organs.

Teeth

About 50 percent of patients with OI have blue or brown teeth that are "opalescent" or milky in appearance. The baby teeth erupt with this color—the color does not develop after eruption. The color difference may first be noted by parents and is usually obvious. Dental abnormalities cannot be prevented, and cleaning will not change the discoloration. The rate of decay can increase if teeth wear away because of poor enamel. The other 50 percent of OI patients have teeth of normal color.

Since the first baby tooth erupts at about six months of age, you can tell at that time whether the rest of the teeth will be affected; if the first baby teeth are white, then the rest of the teeth will be white and there is no need to be concerned about anything except routine dental care.

If, on the other hand, the first teeth are blue or brown, the other baby teeth, as well as some or all of the permanent teeth,



will also be discolored. Dental abnormalities vary widely in individuals with OI, and there appears to be no correlation between the severity of the bone problem and the severity or even the presence of tooth discoloration.

What can you do? First, if your child is diagnosed as having OI at birth, he or she should see a dentist as soon as the first tooth erupts. If the teeth are discolored, they may wear down very rapidly; in fact, they may wear down even before they completely erupt. Fewer than half of the individuals with discolored teeth, however, have severe wear problems. One of the main methods of treatment has been to place crowns over the teeth to prevent them from wearing.

Independence

Parents generally strive throughout their childrens' formative years to teach them principles and skills that will enable them to lead self-sufficient, productive lives as independent of parental influence as possible. For the parent of a child with osteogenesis imperfecta, encouraging independence can be a challenge. While parents realize the value of teaching their child to be independent, they also tend to protect their child with OI by pulling him or her closer to them. Finding the right balance is the key.

Many children with OI who experience much pain in their early years become frightened of sudden movements, of being touched (especially by strangers), or of unfamiliar situations. If a parent can provide as many positive experiences in these situations as possible, the fear can be overridden with confidence. Teach your child that others can be trusted to lift or touch him or her.

We cannot stress enough the importance of allowing others to care for your child while you leave for limited periods of time. Not only does this provide some much needed time on your own for you as parents, but it teaches your child that he or she can function independently without you. You need to teach your child independence, and you, in turn, need to let go.

When instructing your babysitter in the care of your child, remember to repeatedly reassure the sitter. Be sure to mention that fractures can happen no matter how careful one is, and that you would not place blame, just as you cannot blame yourself. Always leave a telephone number where you can be reached, and thoroughly explain handling and emergency procedures. Some parents purchase a

cell phone or pager so they feel assured that they can be easily reached at any time.

Mobility Aids

One of the best ways for a child to achieve independence and confidence is through increased mobility. There are many aids available for helping children achieve maximum mobility. The aids you choose will depend on the severity of the child's condition, the child's muscle strength and gross motor skills, and the recommendations of your physician, physical therapist, or occupational therapist.

Scooters: A scooter is a formed plastic or padded wooden board with four casters on the bottom. The child lies on his or her stomach and uses hands and knees to propel him- or herself along the floor.

Riding toys: There are many inexpensive riding toys on the market. Fisher Price makes a number of small tricycles that can be easily adapted with seat belts, wooden blocks on the pedals for short legs, and back supports for trunk stability. Be sure to choose a tricycle that does not tip easily.

Wheelchairs: There are many excellent wheelchairs available for children. Consult your hospital supply store or your therapists concerning your child's specific needs. Be sure to consider the seat width and look for the most lightweight wheelchair available that meets your child's needs. Many attractive electric wheelchairs are on the market today. Naturally, they are much more expensive than a standard wheelchair and are more cumbersome. However, there are some who believe that the benefits of the enlarged world that is opened up to a child in an electric wheelchair exceeds the loss of muscle tone and development that the child could achieve through pushing a manual wheelchair.

Physical Therapy

It has been found that immobilization of children with OI, either after a fracture or for fear of inflicting new fractures, causes additional osteoporosis (or increased bone brittleness) and muscle wasting because of disuse. These conditions also lead to more fractures. The joint laxity (looseness) associated with OI makes the large joints unstable and adds to the danger of incurring fractures. Therefore, careful positioning and some form of muscle strengthening as soon as possible after the fracture has healed is desirable. Never attempt to limit

your child's spontaneous movement, because any activity will aid in muscle and bone strengthening.

As soon as your child's medical condition permits, you can encourage a full range of exercises, including swimming and weight bearing exercises. Exercise can range from kicking and splashing in the bathtub to a full exercise program implemented by a physical therapist. Weight bearing can begin with propped sitting, head lifting, and partial weight bearing in the upper arms, and can advance to standing and walking. Swimming is the safest and most valuable exercise for children with OI, and should be encouraged as soon as possible.

Bracing

When your child appears ready to stand, you might consider lightweight, containment-type braces for him or her. Braces are initially used with a standing frame or standing table. These devices hold the child who is wearing the braces upright in a standing position. It is hoped that standing will lead to strengthening of the child's fragile bones and, possibly, to long bone growth, thus providing the opportunity for these extremely short children to achieve a little more height.

Walking

Seeing their child walk is a goal for many parents of a child with OI. Because of the different levels of severity of OI, it is very difficult to predict what lies ahead for your child. There are many people with OI who are capable of walking independently for long distances, and others who are able to get in and out of their wheelchairs and walk on a more limited basis. There are others who, even after years of braces, surgery, and physical therapy, are still unable to walk.



The advisable course is for you to proceed as if walking is attainable. Yet it is important to be accepting of whatever your child is able to achieve. Have faith in your child and allow him or her to take the risks necessary to achieve as much independent mobility as possible; love him or her no matter what he or she can accomplish.

Treatment

To date, the only treatment for OI is proper medical and orthopedic management of the symptoms. No cure is known, and no drug or vitamin therapy regimen has been uniformly satisfactory. Researchers continue to make progress with these issues.

The most common means of managing severe deformity from repeated fractures of the long bones is through a procedure called “fragmentation, realignment and intramedullary rod fixation,” or “rodding.” Briefly, this procedure involves straightening the bone and inserting a steel rod through the length of the bone. This procedure is most commonly done in the legs and the arms as needed. Rodding not only corrects bowing (curving) of the bone, but adds an internal support that helps to prevent further fractures. The age of the child on which this operation is performed depends greatly on the size of the bones, but it is frequently done on children as young as two or three years old. When considering this option for your child, be sure to discuss the pros and cons of telescoping and nontelelescoping rods with your orthopedic surgeon. Keep in mind that rodding is a treatment that must be repeated as the child outgrows or rejects the rods.

Schooling and Special Educational Services

Children with OI frequently meet the qualifications for early intervention programs. These programs of specially designed instruction, free to parents, are designed to meet your child’s unique needs, and covers children from birth to age 3. If your child qualifies, you can receive physical and occupational therapy for your child in your home. Contact your local public elementary school or public health department for information or to make arrangements to have your child evaluated (see the Resources section at the end of this publication for additional information).

The case for early “mainstreaming” into the regular classroom seems strong. As adults, most of these children will work in the world of the non-disabled, and as children, they need to associate with all types of children. See the OI Foundation’s “Plan For Success” video and pamphlet for more information about mainstreaming .

Many parents feel that because of the limited exposure to others that their child has during his or her preschool years, a part-time preschool or play group is beneficial. Some preschools ask for volunteer aides to help with protection, toileting, and mobility during this time. It

is ideal to have someone other than a parent perform this function. Parents should observe and evaluate available preschools in their area, selecting one where the physical structure and attitudes of the staff are in harmony with their child's needs.

When the time comes for regular school placement, try to mainstream your child as much as possible. Sometimes mainstreaming involves considerable negotiation with your school district, but the efforts will be rewarding as you see your child blossom.

Conclusion

At first the thought of coping with the problems of parenting a child with a disability may seem overwhelming. Plan to take one day at a time. Get used to your new infant. He or she loves you and needs love in return. Rock, hold, and sing to him or her. Think of your child as a brand new individual who will blossom and grow, much to your delight as parents. In many ways, parenting a child with a disability like OI can be rewarding and exhilarating in ways that a parent would never expect.

Remember that you are not alone. Many other parents have faced situations similar to what you are facing now. It helps to talk to someone who understands. Contact the Osteogenesis Imperfecta Foundation at (800) 981-2663 or via our web site at www.oif.org. We sponsor a program of parent contacts throughout the country, and can probably put you in touch with others in your area who have faced the challenges you are facing.

Additional Reading

- Brazleton, B. (1981). *On becoming a family: The growth of attachment*. New York: Delacorte Press.
- Buscaglia, L. (1983). *The disabled and their parents: A counseling challenge*. New York: Holt, Rinehart, and Winston.
- Featherstone, H. (1981). *A difference in the family: Living with a disabled child*. New York: Penguin Books.
- Finston, P. (1990). *Parenting plus: Raising children with special health needs*. New York: E.P. Dutton.
- Simons, R. (1987). *After the tears: Parents talk about raising a child with a disability*. San Diego: Harcourt.
- Sullivan T. (1995). *Special parent, special child: Parents of children with disabilities share their trials, triumphs, and hard-won wisdom*. New York: Putnam.

Resources

Alliance of Genetic Support Groups

4301 Connecticut Ave. NW, Suite 404
Washington, DC 20008
(800) 336-GENE, (202) 966-5557
www.geneticalliance.org

Association for the Care of Children's Health (ACCH)

1900 Mantua Road
Mount Royal, NJ 08061
(609) 224-1742
www.acch.org

Center for Children with Chronic Illness and Disability

Division of General Pediatrics and Adolescent Health
University of Minnesota
Box 721, 420 Delaware St.
Minneapolis, MN 55455
(612) 626-4032, (612) 624-3939
www.peds.umn.edu/centers

Clearinghouse on Disability Information

Office of Special Education and Rehabilitative Services
Switzer Bldg., Room 3132
330 C Street, SW
Washington, DC 20202-2524

National Easter Seal Society

230 West Monroe Street, Suite 800
Chicago, IL 60606
(312) 726-6200, (800) 221-6827
www.seals.com

National Information Center for Children and Youth with Disabilities

P.O. Box 1492
Washington, DC 20013
(800) 999-5599, (202) 884-8200
E-mail: NICHCY@aed.org
www.nichcy.org

National Maternal and Child Health Clearinghouse

2070 Chain Bridge Road, Suite 450
Vienna, VA 22182
(703) 356-1964, E-mail: nmchc@circsol.com
www.circsol.com/mch

Additional Resources from the OI Foundation

Osteogenesis Imperfecta Foundation has a number of fact sheets, videos, and books that provide additional information for people with OI, their families, and their healthcare providers. Call the Foundation at (800) 981-2663 or (301) 947-0083 or visit our website at www.oif.org for a complete resource listing. Most of the OI Foundation's Information Resources can be downloaded immediately or ordered through our online store.

The following products may be of particular interest, as they cover many of the topics in this pamphlet in greater detail.

You Are Not Alone is a videotape designed to be a companion to this pamphlet. It focuses on the emotional difficulties encountered when a child is diagnosed with OI, and offers practical solutions for caring for infants and toddlers with Type II and severe Type III OI, as well as more mild forms of OI. (**\$5 plus shipping and handling.**)

Plan for Success is a videotape for parents and educators that provides information on integrating children with OI fully into classroom and other school activities. It comes with a companion brochure that has detailed information on applicable laws, adapted physical education, helping peers understand OI, and more. (**\$5 plus shipping and handling.**)

Growing Up With OI is two book set that addresses the specialized needs of children with OI, their parents, siblings and friends. "Families and Caregivers" is written especially for mothers and fathers of infants and children with OI and offers passion, conviction and hope from those who have already experienced living with OI. The "Guide for Children" companion book focuses on the same issues as the adult version, but has been written especially for elementary school readers. (**\$15 per Set, or \$10 each, plus shipping and handling.**)

The Foundation has a series of **fact sheets** on a variety of topics. Visit the Foundation's web site at www.oif.org, or call (800) 981-2663 for a complete listing of fact sheet topics.



Osteogenesis Imperfecta Foundation
804 West Diamond Avenue
Suite 210
Gaithersburg, MD 20878