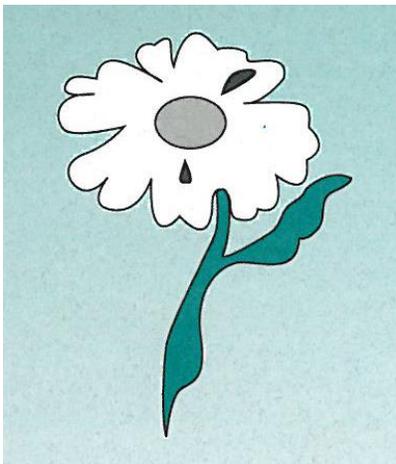


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# **A Prenatal Diagnosis of Spina Bifida and/or Hydrocephalus**

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**Produced by:**

**Spina Bifida and Hydrocephalus Association of Canada**



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## **Introduction**

The Spina Bifida and Hydrocephalus Association of Canada is a network of member associations consisting of individuals with spina bifida and/or hydrocephalus, their parents, families, and friends, and professionals concerned with their care.

Our mission is to improve the quality of life of all individuals with spina bifida and/or hydrocephalus, and their families, through awareness, education, and research.

The purpose of this booklet is to help you understand a prenatal diagnosis of spina bifida and/or hydrocephalus so that you are better able to make informed decisions.

### **You are not alone.**

Many people have been through what you are currently experiencing. We sincerely hope that you will find this booklet helpful, and that you will contact your local spina bifida and hydrocephalus association (see Part 3) if you have any further questions.

This prenatal resource booklet is for informational and educational purposes only. It is not intended to be interpreted as medical advice. Always consult your doctor before making any medical decisions.

To the best of our knowledge the information contained in this booklet was accurate at the time of printing.

Karen Autio  
Chair, Educational Development Committee  
Spina Bifida and Hydrocephalus Association of Canada

# Part 1: Gathering Information

## What now?

Receiving the news that your unborn baby has spina bifida and/or hydrocephalus is never easy.

You may be experiencing a wide range of emotions: uncertainty, worry, grief, shock, fear, numbness, and feeling overwhelmed.

You may have many questions, such as: "How can the doctors be sure there's a problem with my pregnancy?" "What is spina bifida?" "What is hydrocephalus?" "What will it mean for the baby and for the rest of the family?" "What special care will the baby need?" "Should I end the pregnancy?" "Should I have the baby?" "What is this happening to me?"

You are suddenly faced with many decisions and you may feel very isolated - almost as if you are the only person this has ever happened to.

**The purpose of this booklet is to help you answer these questions and understand a prenatal diagnosis of spina bifida and/or hydrocephalus.**

The choices you make will be based on factors unique to your life and your beliefs. Everyone's decisions, and the reasons for those decisions, will be different. Deciding what to do will involve finding a balance among your personal circumstances, priorities, risks and desires. You'll also be thinking about the effect your choices could have on your relationship with your partner, both long and short term. If you have other children, you'll be considering their needs as well.

The process of making informed decisions has several steps:

- **Gathering information.** The first step is to find clear, honest and accurate information about the diagnosis.
- **Thinking about your choices.** Next, you need to think about the information and weigh all possible options. How would each affect you and your family? You may find that it helps to talk about these possibilities with people you trust - your spouse or partner, a religious advisor, a family doctor.
- **Making your decision.** You need to decide what choices are best for you and your family.
- **Looking for support.** Wherever your choices lead you, it's important to know that there are people who can offer advice and support.

These four steps involve asking questions and reaching out for information and advice. This booklet has been organized into three sections to help you make informed choices.

- **Part 1:** offers information about spina bifida and hydrocephalus and their effects. You need to know what a prenatal diagnosis of spina bifida and/or hydrocephalus means so that the choices you make are based on solid information.
- **Part 2:** describe your options and how others might react to your choices.
- **Part 3:** contains sources of information and support - places to look for help both before and after you have made your decisions.

Prenatal diagnosis early in pregnancy allows you to choose whether or not to continue with your pregnancy. It also gives you time to get the information you need to make **informed** decisions. The choice that is right for you is often not clear at first, and may only come into focus gradually.

The responsibility and the choice are yours, but please know that you are not alone. The Spina Bifida and Hydrocephalus Association of Canada offers you our support as you go about the process of making the decisions that are best for you and your family. We've included a list of local associations in Part 3 and we encourage you to contact them.

We hope that learning about spina bifida and hydrocephalus and talking with other parents will help you find your way to the choices that meet your needs.

## **What is spina bifida?**

Spina bifida is a type of neural tube defect. It occurs during the first month of pregnancy, when the central nervous system is forming.

The neural tube forms early in fetal development when a flat plate of cells roll into a hollow column of nerves that extends from the head down the length of the back. In the normal course of development, the neural tube usually closes smoothly, with one end forming the brain and the rest becoming the spinal cord, and after this, the bones of the spine develop.

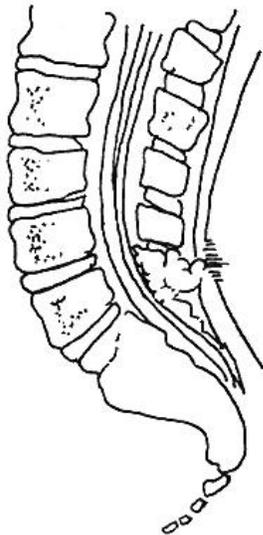
A **neural tube defect** occurs when the neural tube does not close properly. This, in turn, prevents the bones of the spine from closing and leaves part of the spinal cord exposed. The meninges, and sometimes the nerves of the spinal cord, bulge outward through this opening. This prevents the spinal cord from developing normally and interrupts the messages sent from the brain to the affected parts of the body. The amount of damage to the spinal cord and nervous system depends on where the defect is located on the spine and how many nerve pathways are damaged.

**Spina bifida** occurs when there is an opening in the neural tube anywhere along the spine. Spina bifida means "open spine". It is the most common type of neural tube defect.

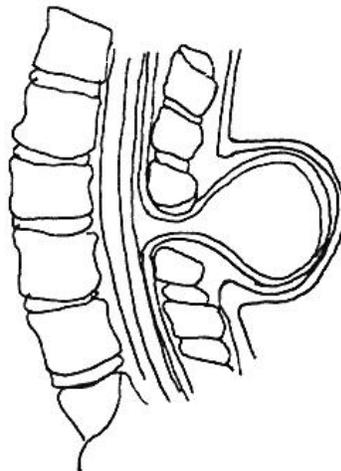
No one knows why neural tube defects happen or what it is that prevents the neural tube from closing properly. Neural tube defects are considered to be "multifactorial disorders". This means that they happen as a result of interactions between an individual's genes and other factors in the environment. Researchers continue to look at the many factors which could cause neural tube defects. However, so far no single cause has been identified.

### What are the types of spina bifida?

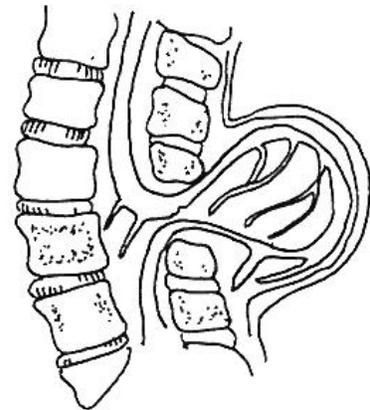
The three most common types of spina bifida are: spina bifida occulta ("hidden"); meningocele (pronounced me-NIN-go-seal); and myelomeningocele (pronounced my-low-meh-NIN-go-seal).



**Occulta**



**Meningocele**



**Myelomeningocele**

**Spina Bifida Occulta:** The outer part of the vertebrae (the bones of the spine) has not completely joined. However, the spinal cord and its covering (the meninges) are undamaged. Often a tuft of hair, dimple, birthmark, or fatty bulge can be found at the site of the defect. Spina bifida icculta cannot be detected prenatally.

**Meningocele:** The outer part of the vertebrae is open, but the spinal cord is relatively unaffected. The meninges are damages and pushed out through the opening in the spine.

**Myelomeningocele:** The outer part of the spine is open and both the meninges (the membranes which cover the spinal cord) and the spinal cord itself are pushed out through the

opening. They are often covered by a thin, fluid-filled sac or cyst. This is the most serious form of spina bifida. Myelomeningocele can damage the nerves of the spine and result in some paralysis of the legs and problems with bowel and bladder functioning. The severity of the disability will depend on where on the spine the opening is located and how many nerves have been damaged. Hydrocephalus may also occur.

### **What causes spina bifida?**

We don't know exactly what causes neural tube defects. As far as we know, they happen as a result of interactions between an individual's genes and other factors in the environment.

Recent research has shown that spina bifida and other neural tube defects are less likely to occur when women get enough of the B vitamin **folic acid** during their childbearing years, either in their diets or through supplements. About 50% of pregnancies are unplanned, and neural tube defects occur during the first month after conception, before most women even know they are pregnant. For this reason, it's important to have a healthy, balanced diet and to be sure you are getting **0.4 mg** of folic acid every day, as long as there is a possibility of becoming pregnant.

If you've already had a pregnancy affected by a neural tube defect, or if you have a family history of neural tube defects, you will need even more folic acid. It's essential that you begin taking **4 mg** of folic acid daily, *at least 3 - 4 months before becoming pregnant*. Even though folic acid is a vitamin, this higher dosage may require a prescription. Talk with your doctor about folic acid supplements as long as there is a possibility of a future pregnancy.

### **What is hydrocephalus?**

Hydrocephalus can develop independently or along with spina bifida. Hydrocephalus occurs when the cerebrospinal fluid (CSF), which everyone's brain produces, can't drain away and builds up in the spaces in and around the brain. In order to control the hydrocephalus, a neurosurgeon operates to place a shunt into those spaces. A shunt is made up of a valve to control the flow of fluid and a soft, flexible plastic tube to carry fluid away from the brain. The shunt is put under the skin and enables the excess fluid to drain from the brain to another part of the body, usually the abdomen. There, the fluid is absorbed into the blood stream. This reduces the pressure on the brain and allows it to continue developing. Hydrocephalus can occur prenatally, while the fetus is still developing, or it can happen soon after birth.

### **What causes hydrocephalus?**

The occurrence of prenatal hydrocephalus is due to a congenital defect or the interaction between an individual's genes and environmental factors.

## **Are they sure about the diagnosis?**

The first step in making decisions is accepting that the decisions have to be made. Many people respond to the news that there is a "problem" in the results of a prenatal test by denying it - "There must be some mistake." "This can't be happening." Accepting that this really *is* happening is not easy.

A prenatal diagnosis of spina bifida and/or hydrocephalus is not made lightly or quickly. It is the result of a careful examination of all the evidence.

For some, the first hint that spina bifida might be present may have been the results of a blood test called **Maternal Serum Screen (MSAFP screen)**. **This test can be drawn and interpreted anytime between 15 weeks 0 days and 23 weeks 6 days gestation. The ideal time for the sample to be drawn is at 16 weeks gestation. If gestational age is uncertain, an ultrasound should be done prior to the blood test to ensure it is interpreted correctly. If there is a positive screen for open spina bifida, genetic counseling will be provided along with a level II or detailed ultrasound and discussion of the option of amniocentesis.**

**Ultrasound** uses sound waves to look inside the womb. The sound waves bounce off the fetus and are converted into a picture on a video screen. If spina bifida is present, the ultrasound examination will show it clearly about 98% of the time if done in a qualified health care centre.

If there is still any doubt about the diagnosis, the next stage of testing is **amniocentesis**. In amniocentesis, a needle is guided through the mother's abdomen into the sac which surrounds the fetus. A small amount of amniotic fluid is removed and tested for levels of alphafetoprotein (AFP) and an enzyme called acetylcholinesterase (ACHE). Amniocentesis can show that the fetus has a neural tube defect, but it cannot show how severe the problem is. Sometimes spina bifida is part of a genetic problem. In this case, amniocentesis may also be used to check the genetic make-up of the fetus.

Right now, a diagnosis of a neural tube defect using amniocentesis is correct 98% of the time. When it is done in the 16th week of pregnancy, amniocentesis has less than **a 0.5% risk** of causing a miscarriage.

## **Will the baby live?**

Today, nearly 90% of all newborns with spina bifida and/or hydrocephalus survive and have the potential to live a normal lifespan. If they receive immediate and continuing medical care, most of these babies will grow up and live meaningful and productive lives.

## **What are the effects of spina bifida and hydrocephalus?**

One of the reasons that it can be difficult to make decisions about how to respond to a prenatal diagnosis of spina bifida and/or hydrocephalus is that the tests can tell you that the conditions exist, but cannot say how severely the child will be affected.

Spina bifida occulta, which is not detected prenatally, may result in such complications as incontinence, weakness of the lower limbs, and back pain. With meningocele, any surgery needed to repair the baby's back is done soon after birth and if no nerves are involved, there are usually no long term effects on the child's development. Physical symptoms may include weakness of the lower limbs and back pain.

Most of the information in this section refers to the effects and impact of the third kind of spina bifida - myelomeningocele - which requires more extensive medical treatment and care.

Spina bifida and hydrocephalus cannot be cured, but they can be treated and managed.

Spina bifida (myelomeningocele) results in damage to the nerves of the spinal cord. Damage to nerves is permanent and cannot be repaired. The damage occurs when some of the nerves in the spinal cord culge out through the opening in the spine caused by spina bifida. Sometimes it helps to visualize the spinal cord as a large cable made up of many small wires. Imagine each of these wires as a nerve pathway. Some of these wires will bulge out through the opening in the spine and be damaged. Others will not. This means that the spinal cord will be able to carry some messages from the brain to the lower part of the body, but will not be able to carry others.

There is no way to know which nerves, or how many nerves, are damaged. This makes it difficult to predict how severely disabled any particular child will be. In general, the degree of impairment is related to where on the spine the damage occurs - the higher the lesion, the more severe the effects. The size of the lesion - the number of vertebrae involved - may also impact upon the degree to which there are physical effects.

Different parts of the body are controlled by nerves in different parts of the spinal cord. In most cases of spina bifida, the opening in the spine occurs in the lower part of the back, in the lumbar and/or sacral regions of the spine. Most, if not all, of the nerves located at the site of the spina bifida lesion and below will be affected in some fashion.

## How Doctors Name Spina Bifida

The bones around the spinal cord are called *vertebrae* or *vertebral bodies*. The vertebral bodies make up the spine, which is divided into different parts.

### NECK

Cervical (C) 7  
bones

### TRUNK

Thoracic (T) 12  
bones

### LOWER BACK

Lumbar (L) 5  
bones

### TAILBONE

Sacral (S) 5  
bones

The bone at the end of the spine is called *Coccyx* or *coccygeal*.

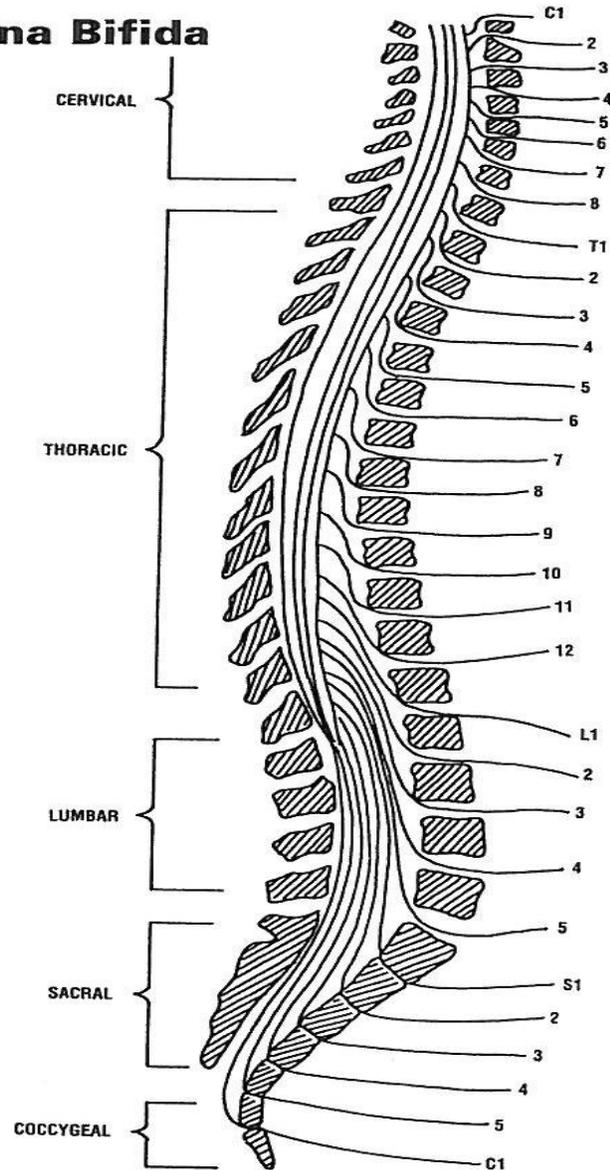
Special nerves called *nerve roots* branch off of the spinal cord at different levels. The nerves are numbered to show where they come out between the vertebral bodies. Each nerve has its effects on certain areas of the body.

Doctors name spina bifida by the highest level of the spinal cord where the nerves work well enough to move a group of muscles.

Example:

L-3 nerve level means the person can kick the lower leg.

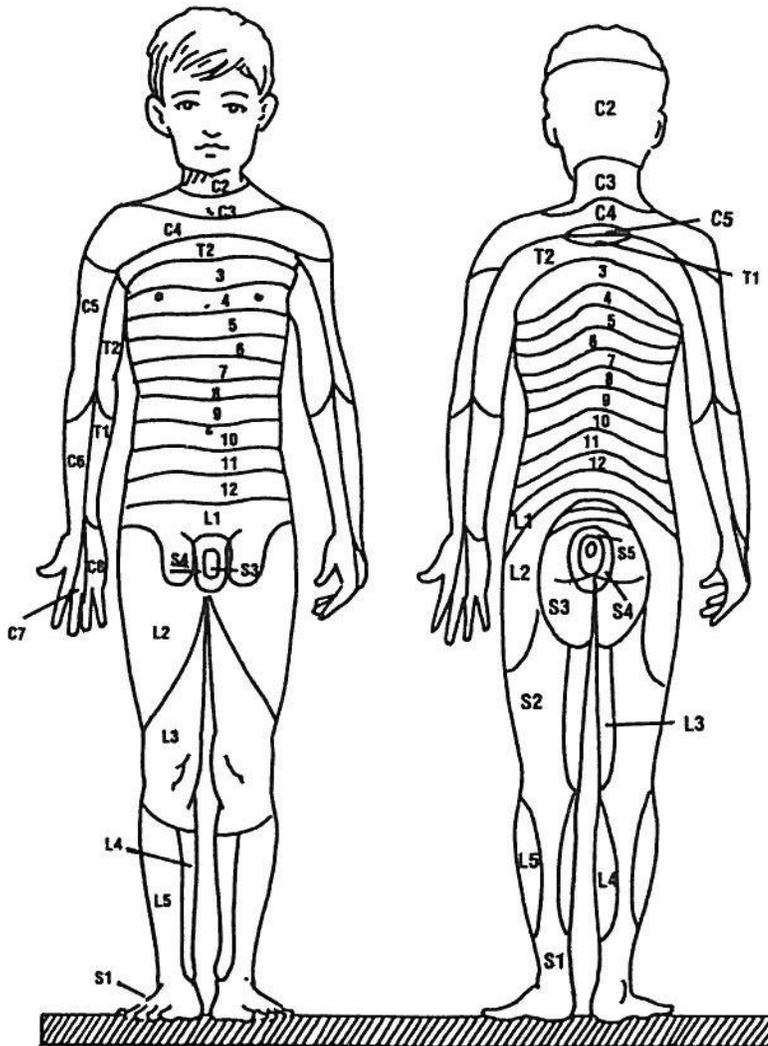
S-1 nerve level means the person can move the ankle up and down.



**SIDE VIEW OF THE SPINAL CORD AND NERVE ROOTS**

## Effects of Spina Bifida on the Nerves

Nerves from the spinal cord branch off to make the arms and legs work. They do this by sending messages to the muscles so they can work in groups. The nerves also help control feeling (sensation), temperature and blood flow to the skin.



**This picture shows where the nerves give sensation to the skin. Each nerve has its effects on its own area of skin.**

People with spina bifida often have poor sensation below the involved nerve level.

- **The lumbar nerves affect the muscles in the legs, knees and feet.** The nerves which pass through the lumbar area of the spine affect the growth of the muscles, ligaments and bones in the legs, all of which contribute to walking. If there is damage to the lumbar nerves, the legs may not be as strong as normal and may not be able to feel sensations like heat, cold, pressure or pain in some areas. In addition, the legs will probably be somewhat smaller than normal because the muscles have not developed properly. All of this can impair walking ability. Again, the amount of impairment is difficult to predict and depends on which nerves have been damaged. For some children, walking is possible with braces or braces with a mobility aid (e.g. walker, crutches, canes), while other children may use wheelchairs.
- **The sacral nerves control the bowel, bladder and sexual function.** If there is damage to the sacral nerves, children may have difficulty with bladder and bowel control. They may not be able to control the muscles that allow for toilet training or be able to feel when their bladder is full or when they need to have a bowel movement. This can cause urine to back up and lead to damage to the kidneys. However, bladder and bowel control can be managed so that children remain healthy and comfortable.

Damage to the sacral nerves may result in some men having problems with sexual functioning when they reach maturity. Sacral nerve damage does not usually affect a woman's ability to bear children, but may cause some problems with sexual functioning due to lack of sensation in the genital area. Pregnancy and/or childbirth may be more difficult for a woman who has spina bifida, and as such, prenatal care by a qualified physician is essential.

The amount of paralysis or impairment will depend on where the opening in the spine occurs and how severely the spinal cord is affected. However, almost all children with spina bifida (myelomeningocele) will have some degree of paralysis and loss of feeling in their legs, and will have problems with bowel and bladder function. In addition, many children with spina bifida also have some form of spinal curvature, i.e. scoliosis, and/or malformation of the legs or feet.

Nearly 90% of babies with myelomeningocele will have hydrocephalus, a build-up of cerebrospinal fluid in and around the brain. Hydrocephalus can occur prenatally or can develop after spinal closure surgery. Difficulties associated with hydrocephalus vary from person to person. They can include: impaired vision, sensitivity to loud noises, headaches, muscle weakness, shunt problems, sensitivity to pressure changes (such as in an elevator or airplane), hormonal imbalances and seizures.

In addition to physical difficulties, children with spina bifida, with or without hydrocephalus, may have some form of learning disability. This means that they may have learning problems in school, even though they may have average or above-average intelligence.

### **How much care do children with spina bifida and/or hydrocephalus need?**

Parents have a central role in fostering the development of a child with special needs. In addition to the care of professionals, some children with spina bifida and/or hydrocephalus require extensive care at home. The amount and kind of care needed varies from child to child, again depending on the severity of the impairment. Parents need to learn new skills and techniques to care for a child with special needs and to help their child develop physically, emotionally, intellectually, socially and spiritually.

A range of medical, health and educational specialists may be involved in a child's care, including pediatricians, neurologists, urologists, neurosurgeons, orthopedic surgeons, physiotherapists, occupational therapists, psychologists and nurses. Further information about the roles of these specialists is found in Part 3. In some hospitals or treatment centres, children are seen by a multi-disciplinary health care team. This allows the children to get many kinds of care in one place. In rural or isolated areas, care can be managed by a local physician, with trips to larger centres for assessment by specialists.

Parents of a child with special needs share the same kinds of worries and concerns that all parents have - after all, a child with special needs is still a child. Each will have his or her own personality and unique way of looking at the world. He or she will grow and go through the same "ages and stages" that all children go through. A baby with spina bifida and/or hydrocephalus needs to be held and cuddles as much as any baby. Parents of toddlers will still need to learn to handle the "terrible twos". A teenager with spina bifida and/or hydrocephalus will have the same interests and feelings common to all teens.

Parents of children with special needs discover that many everyday experiences come with unique challenges for their children. They become advocates for their children, always looking for and working toward the best possible care and educational opportunities. They take them to doctor's appointments, to therapists, and to clinics. Parents may stay in hospital with them during their recovery from surgery. On an ongoing basis, parents watch for complications, like bowel and bladder problems and pressure sores. They help their children to develop the skills they need to be as independent as possible.

## **Will a child with spina bifida and/or hydrocephalus ever be independent?**

Most parents work hard at helping their children develop the physical and social skills they'll need to make their life as independent as possible.

People with disabilities can live independently with varying supports to assist them. They can participate fully and be productive, contributing members of society. However, the concept of independent living is fairly new, and many communities, particularly smaller towns, do not yet provide the necessary services or make all public buildings accessible. This means that individuals sometimes leave their home community in order to live on their own.

In an effort to improve this situation, parents, as well as adults with spina bifida and/or hydrocephalus, have formed support groups to lobby various levels of government for more and better support services and accommodations for special needs. The growing political strength of these groups is making them increasingly effective in improving services for people with these and other disabilities.

## **How will raising a child with spina bifida and/or hydrocephalus affect our family?**

Raising a child with spina bifida and/or hydrocephalus is challenging for everyone in the family. Every family member makes adjustments when a new baby is born. Welcoming a baby with special needs can mean special adjustments.

## Impact on Parents

### Welcome to Holland

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy.

You buy a bunch of guidebooks and make your wonderful plans. The Colosseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

"But there's been a change in the flight plan. They've landed in Holland, and there you must stay."

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy.

But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills. Holland has tulips. Holland has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there.

And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

- Emily Pearl

Parents may feel that raising a child with a disability can have an enormous impact. Even though they love their child deeply, and are prepared to do whatever is necessary to help the child develop fully, they often face a mixture of very strong feelings, which may include love, anger, despair, hope, frustration, and guilt.

Raising a child with a disability can place great strain on a marriage or relationship. Parents must cope with conflicts and tensions, worries and exhaustion.

On the other hand, some couples have said that parenting a child with special needs has strengthened their marriage. This strength is built on communication and partnership, and is born out of overcoming difficulties together, as well as sharing the pleasures and rewards of parenting.

### **Brothers and Sisters**

A sibling with spina bifida and/or hydrocephalus can affect the other children in the family. Children will need their parents' support and love in order to understand and adjust to this new situation. Parents should encourage their children, whenever possible, to develop an independent relationship with their new sibling.

Parents of a baby with spina bifida and/or hydrocephalus, as with any new baby, may be preoccupied and not have as much time for their other children as they used to. Children can feel neglected and resentful. The instinct to protect the child with a disability can easily turn into over-protectiveness and be interpreted as favouritism by other children.

As the baby gets older, the needs may change, but probably won't lessen. Siblings wonder if they'll have to care for their disabled sibling when they grow up. They may worry that when they grow up, their own children could be born with a disability. Parents will need to acknowledge these feelings and help and support their children as they come to terms with them.

How these issues affect children depends to a large extent on how their parents handle the situation. In order to love others, children need to know that they themselves are loved and valued. They need their parents' time, love and attention to help them see their new sibling as an addition to their lives and not as someone who has taken their parents away from them.

### **Financial Effects**

Raising a child with spina bifida and/or hydrocephalus can have a financial impact on the family. Even with extensive medical coverage, there are many direct and indirect costs. You can find out what kind of assistance is available in your community by talking with your local spina bifida and hydrocephalus association, spina bifida clinics or local and provincial governments. Please

refer to Part 3 of this booklet for the contact information of the spina bifida and hydrocephalus association in your area.

### **Challenge and Change**

Raising a child with special needs can mean many changes for a family. But recognizing the challenges they face, and being committed to facing them together, can provide parents with a strong foundation of which to build a family and offer a secure base of support for all of their children.

### **If we have other children, will they have spina bifida too?**

There is a risk that a future child could have spina bifida. In Canada, neural tube defects occur in about 1 of every 750 live births. If spina bifida has already occurred in a previous pregnancy, the chances are about 3% - 5% that it could happen again. You can significantly reduce this risk by taking 4 mg of folic acid daily, at least 3 - 4 months before becoming pregnant. Genetic counselling is recommended as a way to help you discover as much as possible about your own level of risk.

### **Who can we talk to?**

Many people find that talking things over helps them to think things through.

If you are married or in a relationship, you and your partner will be facing these choices and decisions together and both of you will need to work out your feelings.

It's not unusual for a partner to say something like, "It's up to you. Whatever you want is OK with me." It's also not unusual for a partner to assume that you will both naturally want to do the same thing and so no discussion is necessary. It takes a lot of communication to reach a decision that both of you understand, accept, agree on, and can live with comfortably.

Sometimes a partner's pain and anger are so great that participating in decision making is very difficult. As much as possible, ask questions and reach your decisions together.

People who may be able to offer you information, support and an understanding ear, include:

#### **Doctors**

The first person you speak with will probably be your doctor, who will have given you the news about your child's diagnosis. In turn, your family doctor may refer you to a specialist for more detailed information. Doctors can offer you a great deal of technical information about spina bifida and what it means for your pregnancy, childbirth and the baby's health.

### **Other People Who Have Faced This Choice**

Most people find that it's helpful to talk to other parents who have had a similar experience. Talking to parents who have been faced with these choices can help you to find your own path. Those who have been there can truly appreciate your feelings and what you are going through. Contact a counsellor or your local spina bifida and hydrocephalus association for the names of parents who would be willing to talk with you and answer any questions you may have.

### **Counsellors**

Most prenatal diagnosis programs offer counselling services. These counsellors and social workers are trained and experienced in working with people in your situation. If you would like counselling, be sure to ask for it. You may also want to consider grief counselling to help you come to terms with losing the child you were expecting.

### **Religious Advisors**

Depending on your beliefs, you may find it helpful to talk with the hospital chaplain or your own clergy.

Please refer to Part 3 of this booklet for a list of spina bifida and hydrocephalus associations and helpful resource materials.

## **Part 2: Making Choices**

### **What are the options?**

Once you have answers to your questions, gathered some information about spina bifida and/or hydrocephalus, and talked things over with people you trust, the next step is to weigh the options and to think about your choices.

You have three options to consider in deciding how to respond to the prenatal diagnosis of spina bifida and/or hydrocephalus:

- You can continue with the pregnancy, with or without fetal surgery, and make plans to raise your baby.
- You can continue with the pregnancy, with or without fetal surgery, and place the baby for adoption or foster care.
- If the diagnosis is made early enough in your pregnancy, you can terminate the pregnancy.

For many people, these are not easy or clear-cut choices. The choice that seems right for one person or family might not be right for another, even if the circumstances appear to be similar. The important thing to remember is that whatever you decide, it must be your choice. There are many people you can consult for information and guidance, but in the end, it is you and your family who will be directly affected and who will live with the choice you make.

### **What if we continue the pregnancy and raise the baby?**

Prenatal diagnosis has given you time to work through some of your feelings before the baby's birth. You'll need time to adjust and to begin to build new dreams and hopes for the baby who will soon be part of your life. You can focus on the joy that a new baby brings.

Knowing that your baby will be born with spina bifida and/or hydrocephalus allows you time to learn more about your baby's condition, look for resources available in your community, contact other parents and perhaps meet some children and adults with spina bifida and/or hydrocephalus. If you have other children, you'll be able to help them to understand what to expect with the new baby. You'll have time to help your friends and relatives adjust as well.

### **Pregnancy and Childbirth**

Although you may be referred to a specialist, your prenatal care and delivery will probably not be very different than for any other pregnancy. You may be referred to a neurosurgeon or high

risk clinic. You might be given more ultrasounds to check on the baby's head size and development. You will need to take care of yourself during pregnancy as you would with any other: eat well, be active and get regular exercise; avoid smoking, alcohol and drugs; and take only medications prescribed by your doctor.

Whether your baby is born vaginally or by caesarean section will depend on several factors, including your health, the baby's health, the size of the baby's head and the location and size of the baby's spinal lesion. Your doctor will discuss the risks and benefits of each kind of delivery with you. You'll need to work together to decide on the delivery method that balances risks and benefits most effectively and is safest for you and your baby. Be sure to make time to discuss your wishes and concerns with your doctor.

This pregnancy, like most pregnancies, is likely to have its stressful times and you will have many questions. Write down your questions as you think of them and take the list with you when you visit the doctor.

### **Care of a Newborn with Spina Bifida and/or Hydrocephalus**

Planning for your delivery will involve making arrangements for your baby's care immediately after birth. You may want to meet and talk with the specialists who will be involved in caring for your child.

Usually, plans can be made for the birth to occur in a well-equipped medical centre, where there are facilities and specialists available to treat the baby immediately.

As soon as the baby is born, he/she will be given a thorough examination by a pediatrician and a neurosurgeon. After the examination, ask for time to get acquainted with your baby. Discuss with the neurosurgeon what treatment will be most appropriate and when. Surgery to close the opening in the baby's back is usually done as soon as possible after birth to prevent infection and additional damage to the spinal nerves.

The neurosurgeon will assess the baby for signs of hydrocephalus. In some cases, hydrocephalus is evident at birth and a shunt may be implanted immediately (sometimes during the same surgery to close the spina bifida lesion) to control the hydrocephalus. After the shunt has been inserted, the neurosurgeon will continue to check to be sure it is working properly. More surgery may be needed if the shunt becomes blocked or infected. If hydrocephalus is not present at birth, the neurosurgeon will continue to assess the baby for signs of hydrocephalus.

How long the baby stays in hospital will depend on his/her condition.

## **Finding Support and Information in Your Community**

There are many places to look for information, resources and support for raising a child with spina bifida and/or hydrocephalus. Resources and programs available to assist children with disabilities and their families vary from province to province and from community to community. There are also organizations that assist with funding medical equipment and respite to give parents a break from caregiving.

### **Make Contacts**

- **Contact spina bifida and hydrocephalus associations.** Local associations are listed in Part 3 of this booklet. These groups have material to give and to lend, as well as a network of contacts and resource people you can talk with. The association can connect you with other parents. Meeting and talking with these parents and their children will help you get a realistic picture of the challenges and the rewards you may experience. Getting to know people of all ages who have spina bifida and/or hydrocephalus can give you the opportunity to see beyond the disability to real people with meaningful lives. It can help you put spina bifida and hydrocephalus into perspective; help you to recognize and plan for the special needs your baby will have; and help you to prepare to welcome this new person into your life and family.
- **Check the internet.** Caution: not all information on the internet is accurate. Check with your doctor for verification. However, the following sites are both helpful and reputable:
  - Spina Bifida and Hydrocephalus Association of Canada  
[www.sbhac.ca](http://www.sbhac.ca)
  - Spina Bifida and Hydrocephalus Association of Ontario  
[www.sbhao.on.ca](http://www.sbhao.on.ca)
  - Spina Bifida Association of America  
[www.sbaa.org](http://www.sbaa.org)
  - Hydrocephalus Association  
[www.hydroassoc.org](http://www.hydroassoc.org)
  - Children with Spina Bifida: A Resource Page for Parents  
[www.waisman.wisc.edu/~rowley/sb-kids/](http://www.waisman.wisc.edu/~rowley/sb-kids/)
  - Spina Bifida and Hydrocephalus Association of British Columbia  
[www.sbhabc.org](http://www.sbhabc.org)
  - Spina Bifida and Hydrocephalus Association of Quebec  
[www.spina.qc.ca](http://www.spina.qc.ca)

## **Talk with your Doctor and Other Professionals such as Genetic Screening Clinics and High Risk Clinics**

- **Ask for explanations when you don't understand something.** You will be hearing many new words and terms used to explain or describe your baby's condition. Talking with professionals will help you become more familiar with these new terms. When you hear a word you don't understand, don't hesitate to ask for an explanation. The more you know, the more prepared you'll be and the better able you'll be to participate in your baby's care.
- **In some places there are support groups for parents of children with disabilities.** Many people have found these to be very helpful. Being faced with this diagnosis can be a traumatic and difficult experience. Most genetic screening clinics have social workers and/or counsellors who will talk with you and put you in contact with support groups. You may also want to consider grief or other counselling.
- **contact your provincial Department of Health, your local health unit, and the nearest children's hospital and spina bifida clinic.**
- **visit your library** and ask the librarian for help in locating the most current books and articles.

## **Communicate**

Welcoming a child with spina bifida and/or hydrocephalus calls upon parents' resources of strength, love, courage and creativity. Knowing about your baby's condition prenatally gives you and the other people in your life the gift of time. Parenting a child with special needs is sometimes a difficult journey, however, many who have travelled it have found it to be most rewarding and worth the effort.

## **What if we place the baby for adoption or foster care?**

You might consider this option if you decide that you do not have the support systems or resources that will allow you to raise a child with spina bifida, but at the same time, do not chose to terminate your pregnancy.

- **Information about Adoption Procedures**

Regulations and procedures governing adoption and foster care vary from place to place. If you are considering adoption or foster care, talk with your doctor, who will be able to put you in touch with adoption agencies and with the community services department in your province. There are people who wish to adopt and who are able to

care for a child with special needs. You'll need help to explore all of the options and make the best possible arrangements for your baby.

- **Counselling and Support**

In some places there are support groups for those who have placed children for adoption. Many people have found these to be very helpful. Most genetic screening clinics have social workers or counsellors who will talk with you and put you in contact with support groups. You may also want to consider grief or other counselling.

Resource materials related to adoption are listed in Part 3 of this booklet.

### **What is fetal surgery?**

Fetal surgery for spina bifida is an option available only to carefully selected cases at a limited number of hospitals. This procedure **cannot** cure the disorder or restore any lost neurological function, but hopefully it may lessen the physical and neurological damage to the baby.

Surgical repair of the spina bifida lesion is usually performed between 21 and 30 weeks gestation, via a hysterotomy. Both the mother and the baby are anesthetized, and an epidural is used to numb the uterus in order to prevent contractions. The uterus is lifted out of the mother and placed on her abdomen. A small incision is made in the uterus, allowing access to the baby's back. Once the neurosurgeon has surgically repaired the spina bifida lesion, the uterus is placed back inside the mother, and the pregnancy continues for as long as possible.

In some cases, although there was evidence of the potential for hydrocephalus during prenatal surgery, a shunt was not needed at birth. There remains the possibility that one may be required later.

There are many risks associated with this type of surgery. Risks for the mother may include infection and bleeding. Risks for the fetus may include blood transfusion, brain hemorrhage, organ immaturity, and possibly death. Premature delivery with this type of surgery is the norm. Prevention of premature labour and delivery depends upon the effectiveness of medications and bed-rest. If delivery happens too early, then the child is at risk for developing conditions associated with prematurity. These can include learning disabilities, eye problems, low birth weight and shortened stature throughout life, and possibly even death.

Despite the risks involved, fetal surgery is a marvellous breakthrough. The few infants who have successfully undergone this procedure show promising neurological

outcomes. It is important to note, however, that this procedure is in the experimental stages and that children born after having fetal surgery still have significant persisting disabilities.

## **What happens if we decide to terminate the pregnancy?**

If you decide to terminate your pregnancy you'll need to learn what's involved in the procedure, make decisions about how you will say goodbye and grieve for your loss, and find out about local counselling services or support groups.

- **Pregnancy Termination**

**The method of termination used depends mainly on the stage of pregnancy and the size of the fetus. Factors such as your health status, personal preference and location of the procedure can also impact which method is used.**

**Often the procedure is performed using one of two methods: Dilation and Evacuation (D&E) or medical induction. Other methods may be available however and all options should be thoroughly discussed with your healthcare provider.**

**Dilation and Evacuation (D&E):**

**This method is usually performed prior to 20 weeks gestation. It requires multiple laminaria tents (a natural product) to be inserted into the cervix to gradually dilate the cervix.**

**Medical Induction:**

**This method is typically performed in the second trimester where medication is utilized to induce the labour process. This procedure is done in the hospital and often requires an overnight stay.**

**Regardless of the procedure, a detailed discussion with your healthcare provider is recommended so you know what to expect.**

- **Saying Goodbye**

This is a sad and difficult time. Some people view this as the end of a pregnancy. Others experience it as the death of a child. In either case, you are facing a loss. You will feel grief and will need to think about how you want to say goodbye. There are no rules and no right or wrong ways to deal with this situation. You

need to do whatever will help you through this difficult time. Talking to a trusted friend and/or counsellor may be helpful.

- **Counselling Services and Support Groups**

Within a very short period of time you will have experienced some of the most upsetting news, the most difficult decisions, and the most painful losses of your life. Although your pregnancy will have ended relatively quickly, your feelings, and those of your partner, may not. You may find out that you and your partner have very different ways to cope with this issue, and it may be difficult to understand this difference. It is normal to need time to heal. It is also normal to need help during this process and you may wish to seek counselling.

In some places there are support groups for parents in your situation, and many parents have found these to be very helpful. Most genetic screening clinics have social workers and/or counsellors who will talk with you and put you in contact with support groups. Your local spina bifida and hydrocephalus association may also be able to put you in touch with these services (see Part 3 for further contact information).

## **How might others react to your decision?**

Please recognize that whatever choice you make, you will grieve, for each choice entails a loss.

- If you choose to continue your pregnancy, you will grieve for the loss of the child you had imagined and the vision of parenthood you had dreamed about.
- If you choose to place your baby for adoption or foster care, you will mourn the loss of your child.
- If you choose to terminate the pregnancy, you will also grieve for the baby.

Whatever decision you make, you may have traumatic and difficult experiences. As you deal with your grief and pain, you may find that some of the people around you don't understand what you're going through. It takes time to work through grief. Even with the best intentions, people may sometimes try to rush you and urge you to get on with your life. You may find that you need time, support and assistance to come to terms with what has happened, to make it part of your life, and to move on.

Your grief and pain are real. Knowing that you have made the best choice for yourself and your family does not make that choice painless or easy to live with. It will take time, love and

support to work through your feelings, but they will be even more difficult to bear if you push them away or deny them.

The decision you make is personal and private, and you may find it difficult to talk about. Whatever your decision, there will be those who support you and respect your choice, and those who will judge you and disagree with your choice. There will be people who will consider you selfish for choosing to bring a child with a disability into the world. There are other people who will think that you are selfish for choosing not to.

Everyone has different beliefs about what is ethically, morally or socially correct. There is no one "right" choice. All you can do is ask questions, weigh your options, and make the decision that is best for you.

Once you've made a decision and acted on it, you may feel a flood of relief. Soon after, however, you may begin to question and second-guess yourself. This is a normal and common reaction to any major decision. You may find that certain days or situations trigger your doubts and questions. For example, mother who have chosen to terminate a pregnancy may find that the anniversary of the procedure or of their due date is a time of painful recollection and questioning. Those who have chosen to continue their pregnancy may question their choice when their child struggles or is in pain.

These feelings do not mean that you have made the wrong choice. Knowing that you worked through your choices carefully as part of your decision-making process can help ease these feelings and be a source of reassurance when they occur.

### **Wrestling with a difficult decision? You are not alone.**

Whatever decisions you make about your pregnancy, remember that you are not alone. Other parents have been in your place and have wrestled with the same difficult choices. Although your decisions will be deeply personal and you alone must make them, the experience and perspective you can get from other parents, spina bifida and hydrocephalus associations, counsellors and health professionals may help you to see more clearly.

Talk with people you trust. Read all the up-to-date information you can find. Think about your choices and what they will mean for you and your family. Then make your decisions from a foundation of information and support.

**No matter what your choice, the spina bifida and hydrocephalus associations across Canada wish you well and offer you their continued support.**

## **PART 3: More Information and Support**

### **Spina Bifida and Hydrocephalus Associations**

Spina bifida and hydrocephalus associations work to improve the quality of life for all individuals with spina bifida and/or hydrocephalus, and for their families. These groups offer personal support, advocacy and information on any aspect of spina bifida and hydrocephalus.

- **Spina Bifida and Hydrocephalus Association of Canada (SBHAC)**

Suite 647 - 167 Lombard Avenue

Winnipeg, Manitoba R3B 0V3

Phone: 800-565-9488

204-925-3650

Fax: 204-925-3654

E-Mail: [info@sbahc.ca](mailto:info@sbahc.ca)

Website: [www.sbhac.ca](http://www.sbhac.ca)

In order to obtain current contact information for any of the following association in Canada, call the SBHAC toll free number, 1-800-565-9488:

- Spina Bifida and Hydrocephalus Association of British Columbia
- Spina Bifida and Hydrocephalus Association of Southern Alberta
- Spina Bifida and Hydrocephalus Association of Northern Alberta
- Spina Bifida and Hydrocephalus Association of Saskatchewan South
- Spina Bifida and Hydrocephalus Association of Saskatchewan North
- Spina Bifida and Hydrocephalus Association of Manitoba
- Spina Bifida and Hydrocephalus Association of Ontario
- L'Association de spina-bifida et d'hydrocéphalie du Québec
- Spina Bifida and Hydrocephalus Association of Nova Scotia
- Spina Bifida and Hydrocephalus Association of Prince Edward Island

## Printed Resources

- **Prenatal Hydrocephalus - A Book For Parents**

Written for expectant parents with the purpose of providing information about the diagnosis of prenatal onset hydrocephalus. Produced by the Hydrocephalus Association, San Francisco, California.

\$2.00 US

Available from: Hydrocephalus Association  
4340 East West Highway, Suite 905  
Bethesda, MA 20819 USA  
(301) 202-3811  
Email: [info@hydroassoc.org](mailto:info@hydroassoc.org)

- **When your unborn baby has a problem - How to manage the weeks ahead**

A booklet for families produced by SAFDA: Support After Fetal Diagnosis of Abnormality, and the NSW Genetics Education Program, Sydney, Australia

Available from: SBHAC  
800-565-9488  
Email: [info@sbhac.ca](mailto:info@sbhac.ca)

- **A Time to Decide, A Time to Heal**

Molly A. Minnick M.S.W.

Kathleen J. Delp, A.C.S.W.

Mary C. Ciotti, M.D.

Parents share their experiences around making decisions when faced with an unfavourable prenatal diagnosis. Covers decision-making, taking control, and long term feelings about choices. Very thorough and compassionate.

\$9.95 (US)

Available from: Pineapple Press  
PO Box 312  
St Johns, MI 48879 USA  
or  
[www.amazon.com](http://www.amazon.com)

- **"Difficult Decisions" for Families Whose Unborn Baby Has a Serious Problem**  
 Excellent Resource  
 \$3.95 (plus postage and handling)  
 Available from: Parent Books  
 201 Harbord Street  
 Toronto, ON M5S 1H6
- **A Heartbreaking Choice**  
 A newsletter for parents who have interrupted a pregnancy after prenatal diagnosis has revealed fetal abnormalities.  
 Website: [www.aheartbreakingchoice.com](http://www.aheartbreakingchoice.com)
- **Precious Lives, Painful Choices**  
 Sherokee Ilse  
 Written for parents who "find themselves in the position of having to decide, under great pressure and with little guidance available, the fate of their baby during pregnancy." Covers all choices thoroughly and non-judgmentally.  
 \$12.95 (US)  
 Available from: Wintergreen Press  
 3630 Eileen Street  
 Maple Plain, MN 55359 USA  
 or  
 ICEA Bookcentre  
 PO Box 20048  
 Minneapolis, Minnesota 55420 USA  
 or  
[www.amazon.com](http://www.amazon.com)
- **Given in Love**  
 A book for young mothers considering adoption. Recognizes the birth mother as giver and griever.  
 \$3.50 (US) plus shipping and handling  
 Available from: The Centering Corporation  
 7230 Maple Street  
 Omaha, Nebraska 68134 USA  
 402-553-1200  
 website: [www.webhealing.com/centering/index.html](http://www.webhealing.com/centering/index.html)

or  
www.amazon.com

- **SAFTA: Support Around Termination For Abnormality**  
SAFTA publishes a handbook for parents and a newsletter.  
73 Charlotte Street  
London W1P 1LB  
Phone: 0171 631 0280  
Parents' Helpline: 0171 631 0285

## **Who's Who is Spina Bifida and Hydrocephalus Care Programs**

**Genetic Counsellor and/or Geneticist.** Healthcare professionals trained to offer support and help to assess the chance of occurrence or recurrence of a congenital disorder such as spina bifida.

**Neurologist.** A physician who specializes in the physiological functions of the brain and nervous system.

**Neurosurgeon.** A physician who specializes in the care of the brain and spinal cord. If hydrocephalus is present, it is the neurosurgeon who will insert a shunt and continue to evaluate its function.

**Occupational Therapist.** A therapist specializing in child development trained to assess children's skill levels, especially in the areas of the motor skill and hand-eye coordination.

**Orthopedic Surgeon.** A physician who specializes in the treatment and surgery of bones, joints, and muscles.

**Pediatrician.** A physician who specializes in the care of infants and children.

**Physiotherapist.** A therapist who provides treatment and instruction to build strength and range of motion that increases mobility.

**Psychologist.** A physician who is concerned with the psychodevelopment of the child. Developmental testing can identify medical and educational issues which need to be addressed.

**Social Worker.** An individual who is trained to offer support and to assist in accessing support services within your community.

**Urologist.** A physician who specializes in problems and surgery of the urinary tract.

## Glossary of Terms

**Alpha-fetoprotein (AFP).** A protein produced by the fetus and found in the amniotic fluid. AFP may be measured in the amniotic fluid or the blood of the pregnant woman to test for spina bifida.

**Anencephaly.** A neural tube defect in which the top of the neural tube fails to close, resulting in the absence of a major portion of the brain, skull, or scalp.

**Cerebrospinal fluid (CSF).** The fluid produced by the brain that circulates throughout the central nervous system and protects the brain and the spinal cord.

**Congenital.** A condition that exists at birth.

**Encephalocele.** A neural tube defect in which the brain, meninges, or both protrude through an opening in the skull.

**Folic Acid.** A "B" vitamin which enables the body to form proteins and genetic material necessary for normal fetal development. It also helps to form hemoglobin, which carries oxygen through the blood. Folic acid is sometimes called "folacin" or "folate".

**Gestation.** Period of development from the time of fertilization of the ovum to birth.

**Hydrocephalus.** A condition in which fluid builds up in the ventricles (spaces) in the brain, which results in compression of the brain and eventually enlargement of the head.

**Hysterotomy.** Incision in the uterus.

**Incontinence.** Inability to control urination and/or bowel movements.

**Lesion.** In spina bifida, lesion refers to the area on the spinal column where the opening occurs.

**Meninges.** The membranes (tissue) surrounding the brain and spinal cord.

**Meningocele.** A rare type of spina bifida which primarily affects the coverings around the spinal cord.

**Meningomyelocele.** Another word for myelomeningocele.

**Myelomeningocele.** The most involved form of spina bifida. Part of the spinal cord and the meninges protrude through an opening in the vertebrae. Babies born with myelomeningocele may also have hydrocephalus.

**Neural tube.** The tissue in a developing fetus which eventually forms into the brain and spinal cord.

**Neurological.** Function of the brain and nervous system.

**Paralysis.** Complete or partial loss of muscle movement.

**Prenatal.** Before birth.

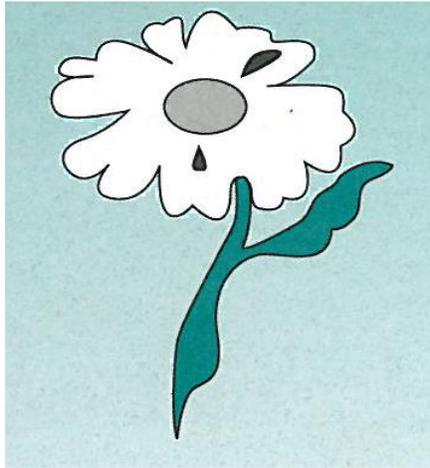
**Shunt.** A plastic tube surgically inserted in the brain which redirects cerebrospinal fluid, usually to the abdomen.

**Spina bifida.** A congenital malfunction of the spine characterized by failure of the vertebrae to fuse or close. The three types of spina bifida are myelomeningocele, meningocele, and occulta.

**Spina bifida occulta.** The mildest form of spina bifida. Occulta means hidden. Spina bifida occulta is the failure of the bony fusion of the vertebrae with no involvement of the meninges or spinal cord.

**Uterus.** Womb.

## The Association's Symbol is the Daisy.



The **heart of the flower** represents the brain, which in the case of persons living with **Spina Bifida**, is often affected by hydrocephalus.

The **daisy's petals** are cloven, thereby representing the various lesions caused by **Spina Bifida** and hydrocephalus.

The **daisy's leaf** and stem are irregular, and depict the unusual form of the spinal cord and backbone of a person who has **Spina Bifida**.

The **beauty** of a flower is equally meant to reflect the beauty of people with **Spina Bifida** who, in spite of their challenges, live happy and productive lives.

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**Spina Bifida & Hydrocephalus Association of Canada**

**647 - 167 Lombard Avenue**

**Winnipeg, MB R3B 0V3**

**Phone: 204-925-3650**

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