GROWING UP WITH SPINA BIFIDA. pdf

1: Living With Spina Bifida (Infants) | CDC

challenges of growing up for all youth and are most evident during the adolescent years; however, youth with spina bifida reported increased difficulties with these issues, possibly related to the.

References Having a new baby is an exciting and challenging time. The same is true for parents who have a child affected by spina bifida. However, in addition to adjusting to life with a new baby, parents of a child with spina bifida also need to learn as much as possible about the condition to prepare for the needs of their child. Learning about Spina Bifida When parents find out they are going to have a child with spina bifida, it can be overwhelming. Parents need to know about spina bifida and understand the health issues and treatment options to make the best possible choices for the health and happiness of their child. Parents should talk with a health care provider about any questions or concerns they have. Health issues will be different for each baby. Some babies have issues that are more severe than other babies. With the right care, babies born with spina bifida will grow up to reach their full potential. Hydrocephalus Many babies born with spina bifida get hydrocephalus often called water on the brain. This means that there is extra fluid in and around the brain. The extra fluid can cause the spaces in the brain, called ventricles, to become too large and the head can swell. Hydrocephalus needs to be followed closely and treated properly to prevent brain injury. If a baby with spina bifida has hydrocephalus, a surgeon can put in a shunt. Additional surgery might be needed to change the shunt as the child grows up or if it becomes clogged or infected. For more information, please visit the Spina Bifida Association website: Hydrocephalus and ShuntsExternal Mobility and Physical Activity People affected by spina bifida get around in different ways. These include walking without any aids or assistance; walking with braces, crutches or walkers; and using wheelchairs. People with spina bifida higher on the spine near the head might have paralyzed legs and use wheelchairs. Those with spina bifida lower on the spine near the hips might have more use of their legs and use crutches, braces, or walkers, or they might be able to walk without these devices. Doctors can start treatment for movement problems soon after a baby with spina bifida is born. Regular physical activity is important for all babies, especially for those with conditions that affect movement, such as spina bifida. There are many ways for babies with spina bifida to be active. For example, they can: Play with toys, such as activity mats. Enjoy parks and recreation areas. Participate in community programs, such as the Early Intervention Program for Infants and Toddlers with Disabilities, which is a free program in many communities. Do exercises recommended by a physical therapist. For more information, please visit the following websites:

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2: My Journey to Self-Love With Spina Bifida | The Mighty

Spina bifida remains one of the leading cause of infantile paralysis in the world. While it primarily affects the brain and spinal cord, it also impacts related body systems such as bowel, bladder.

Many people have stereotypes of how people with disabilities live their lives. I always say having a disability was my biggest blessing. Being in and out of hospitals was definitely not fun. But even then I never complained. When I look back, all the great times I had make the bad memories fade. Having a disability can be difficult sometimes but when I achieve something, it makes it even that more special, because I know I had to work really hard to get there. I realized that if I got mad at every little comment or stare or inconvenience I would be an unhappy person, and I did not want that for myself. So I chose happiness. Everyone has bad days. We are all human, but because I know what pain is, I am able to feel and appreciate happiness so much more. All of the not so great things that happened in my life are a part of me. All of the good and the bad experiences make me the person I am today, and I have a different perspective on life because of it. I embraced every little thing about myself, wheelchair and all. One of my favorite things about being in a wheelchair is getting to connect with other people with disabilities, especially children. I went to elementary school, middle school, and high school being the only one in a wheelchair. It was hard because I stuck out a lot, but I think that was also my favorite part. I loved being unique and different from everyone else. I was not able to flip through a magazine and see a woman in a wheelchair. I was not able to turn on the TV and see a movie or a show starring a character in a wheelchair. There were no advertisements in the beauty industry featuring women in wheelchairs. This is so damaging to the confidence of children and adults. Society should not determine how you think of yourself. Not even the girls in the magazines look like that in real life. The moment I truly accepted myself, I was truly happy. Everyone has beauty and you should be the first one to see it. I am so happy with my life and comfortable in my skin that sometimes people ask me how I got so confident. I realized that my body fought through 24 surgeries to keep me alive; how could I not love it back? Acceptance is everything to me, and I would much rather spend my life living it to the fullest than sit around and complain about all the little things. We need to look forward and see there is so much beauty in everyone and everything. This world is full of people who are different, and that is my favorite thing about it. People with disabilities are able to live happy lives and are able to love themselves and to be comfortable with who they are. I want to be the person I needed when I was little. I hope in the future girls like me can open a magazine and see someone they can relate to and know they are not alone. And if you are someone who is struggling with loving yourself or your life, I believe you too can do it. Start focusing on the things that make you happy and the things you love about yourself, because you deserve it. To all the young girls who are in wheelchairs and feel alone, know you are not. Know you are beautiful, powerful and strong and embrace your differences, because when you do you will become unstoppable. Who was he to say what kind of quality of life I would have? Fast forward to the present. I am a speaker and a disability advocate. I am a completely independent person who drives, goes to school and is able to live their life just like any other 22 year old. I grew up with an amazing family and great friends who always supported me in every single thing I did. I had everything any child could ever ask for and more. So looking back at what the doctor said, I guess he was right after all. Follow the author below for more great content. Getty photo by Werner Images. Find this story helpful? Share it with someone you care about.

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3: Growing Up with Spina Bifida: Linnea Wintersâ€™ Story

Growing Up with Spina Bifida sessions are held in Lexington and Louisville, creating the opportunity for hundreds of individuals to interact and learn in this great program. Navigating obstacles is one of the most important tools SBAK can provided parents and individuals affected by SB.

It falls under the broader category of neural tube defects. Normally, the neural tube forms early in pregnancy, and it closes by the 28th day after conception. In babies with spina bifida, a portion of the neural tube fails to develop or close properly, causing defects in the spinal cord and in the bones of the spine. Spina bifida can range from mild to severe, depending on the type of defect, size, location and complications. The exposed nervous system may become infected, so prompt surgery is needed after birth. Spina bifida can occur in different forms: The severity of spina bifida depends on the type, size, location and complications. Spina bifida occulta "Occulta" means hidden. The mildest form, spina bifida occulta results in a small separation or gap in one or more of the bones of the spine vertebrae. Meningocele In a form of spina bifida called meningocele, the protective membranes around the spinal cord meninges push out through the opening in the vertebrae, forming a sac filled with fluid. Myelomeningocele Also known as open spina bifida, myelomeningocele is the most severe form. The spinal canal is open along several vertebrae in the lower or middle back. This makes the baby prone to life-threatening infections. Symptoms Signs and symptoms of spina bifida vary by type and severity. Symptoms can also differ for each person. In this severe form of spina bifida: The spinal canal remains open along several vertebrae in the lower or middle back. Both the membranes and the spinal cord or nerves protrude at birth, forming a sac. Tissues and nerves usually are exposed, though sometimes skin covers the sac. When to see a doctor Typically, meningocele and myelomeningocele are diagnosed before or right after birth, when medical care is available. These children should be followed by a specialized team of doctors throughout their lives and families should be educated on the different complications to watch for. As with many other problems, it appears to result from a combination of genetic and environmental risk factors, such as a family history of neural tube defects and folate deficiency. Risk factors Spina bifida is more common among whites and Hispanics, and females are affected more often than males. Folate vitamin B-9 is important to the healthy development of a baby. Folate is the natural form of vitamin B The synthetic form, found in supplements and fortified foods, is called folic acid. A folate deficiency increases the risk of spina bifida and other neural tube defects. Family history of neural tube defects. That risk increases if two previous children have been affected by the condition. In addition, a woman who was born with a neural tube defect has a greater chance of giving birth to a child with spina bifida. However, most babies with spina bifida are born to parents with no known family history of the condition. Pre-pregnancy obesity is associated with an increased risk of neural tube birth defects, including spina bifida. Some evidence suggests that increased body temperature hyperthermia in the early weeks of pregnancy may increase the risk of spina bifida. Elevating your core body temperature, due to fever or the use of saunas or hot tubs, has been associated with a possible slight increased risk of spina bifida. If you have known risk factors for spina bifida, talk with your doctor to determine if you need a larger dose or prescription dose of folic acid, even before a pregnancy begins. If you take medications, tell your doctor. Some medications can be adjusted to diminish the potential risk of spina bifida, if plans are made ahead of time. Complications Spina bifida may cause minimal symptoms or only minor physical disabilities. If the spina bifida is severe, sometimes it leads to more significant physical disabilities. Severity is affected by: The size and location of the neural tube defect Whether skin covers the affected area Which spinal nerves come out of the affected area of the spinal cord This list of possible complications may seem overwhelming, but not all children with spina bifida get all these complications. And these conditions can be treated. Walking and mobility problems. Whether a child can walk typically depends on where the defect is, its size, and the care received before and after birth. Children with myelomeningocele can have a variety of problems in the legs and spine because of weak muscles in the legs and back. The types of problems depend on the level of the defect. Possible problems include a curved spine scoliosis , abnormal growth or dislocation of the hip, bone and joint deformities, muscle contractures and other

orthopedic concerns. Bowel and bladder problems. This is because the nerves that supply the bowel and bladder come from the lowest level of the spinal cord. Accumulation of fluid in the brain hydrocephalus. Babies born with myelomeningocele commonly experience accumulation of fluid in the brain, a condition known as hydrocephalus. Shunts can stop working or become infected. Warning signs may vary. Chiari malformation type II. Chiari malformation kee-AH-ree mal-for-MAY-shun type II is a common brain abnormality in children with the myelomeningocele form of spina bifida. The brainstem, or lowest part of the brain above the spinal cord, is elongated and positioned lower than usual. This can cause problems with breathing and swallowing. Rarely, compression on this area of the brain occurs and surgery is needed to relieve the pressure. Infection in the tissues surrounding the brain meningitis. Some babies with myelomeningocele may develop meningitis, an infection in the tissues surrounding the brain. This potentially life-threatening infection may cause brain injury. Tethered spinal cord results when the spinal nerves become bound to the scar where the defect was closed surgically, making the spinal cord less able to grow as the child grows. This progressive tethering can cause loss of muscle function to the legs, bowel or bladder. Surgery can limit the degree of disability. Both children and adults with spina bifida, particularly myelomeningocele, may have sleep apnea or other sleep disorders. Assessment for a sleep disorder in those with myelomeningocele helps detect sleep-disordered breathing, such as sleep apnea, which warrants treatment to improve health and quality of life. Children with spina bifida may get wounds on their feet, legs, buttocks or back. Sores or blisters can turn into deep wounds or foot infections that are hard to treat. Children with myelomeningocele have a higher risk of wound problems in casts. Children with spina bifida have a higher risk of latex allergy, an allergic reaction to natural rubber or latex products. Latex allergy may cause rash, sneezing, itching, watery eyes and a runny nose. It can also cause anaphylaxis, a potentially life-threatening condition in which swelling of the face and airways can make breathing difficult. More problems may arise as children with spina bifida get older, such as urinary tract infections, gastrointestinal GI disorders and depression. Children with myelomeningocele may develop learning disabilities, such as problems paying attention, and difficulty learning reading and math. Prevention Folic acid, taken in supplement form starting at least one month before conception and continuing through the first trimester of pregnancy, greatly reduces the risk of spina bifida and other neural tube defects. Several foods, including enriched bread, pasta, rice and some breakfast cereals, are fortified with mcg of folic acid per serving. Folic acid may be listed on food packages as folate, which is the natural form of folic acid found in foods. This vitamin is present naturally in many foods, including:

4: Spina bifida - Wikipedia

Growing up with spina bifida, a birth defect that affects the spine, I was never physically active. I believed my disability excluded me from keeping fit. My peers would ridicule me in gym class because I could not keep up.

Even your social life takes a hit. Which leads me to a biggie: I never dated in high school. Seeing my friends pair off and start dating made me feel like an outsider. But you know what you avoid by not dating in high school? I also know the first thing that comes to your mind: Your scar will show. When you have a disability and are out in the world, the biggest tool you have at your disposal is your confidence. It disarms the stares of those around you. Some may still stare, but it will be because they are in awe of your confidence. Choose confidence and you will win every time. But your biggest obstacle as a teenaged girl with spina bifida? Learning how to handle bowel and bladder accidents. Know your triggers, such as diet, and avoid things that turn your bowels and bladder into a tsunami. For me, it was avoiding caffeine. Weather can also be a factor. Say it is the middle of summer, hotter than blitz, and you go out to the mall. Using crutches to walk, you step inside the first store. The AC is on full blast. The same thing happens in winter when you go from cold to hot suddenly. First, catheterize before leaving the house. If taking your chair is not possible, you can still get by with using crutches. Just make sure to wear a disposable pair of underwear over your actual panties. These were a lifesaver for me in college. Finally, make sure when you go out that you have plenty of catheters. I remember once when my grandparents and I drove my parents to the airport. The trip took longer than we thought and my parents missed their flight. So we had to take them on to their next destination â€” a two-hour drive. Guess who forgot to take extras with her? But even with a vigilant diet and making sure to catheterize at regular intervals, accidents happen. So what do you do? It lessens the embarrassment for you, and makes sense to the other person who expects this based on your stage of life. After all, it does eventually get better. This post originally appeared on Be Anxious About Nothing. Find this story helpful? Share it with someone you care about.

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5: Spina bifida - Symptoms and causes - Mayo Clinic

Growing up with a disability was definitely different, but not in a terrible way as people may think. Many people have stereotypes of how people with disabilities live their lives. Many people have stereotypes of how people with disabilities live their lives.

Treatment[edit] There is no known cure for nerve damage caused by spina bifida. Standard treatment is surgery after delivery. This surgery aims to prevent further damage of the nervous tissue and to prevent infection; pediatric neurosurgeons operate to close the opening on the back. The spinal cord and its nerve roots are put back inside the spine and covered with meninges. In addition, a shunt may be surgically installed to provide a continuous drain for the excess cerebrospinal fluid produced in the brain, as happens with hydrocephalus. Shunts most commonly drain into the abdomen or chest wall. Pregnancy[edit] Standard treatment is after delivery. There is tentative evidence about treatment for severe disease before delivery while the baby is inside the womb. The first is open fetal surgery, where the uterus is opened and the spina bifida repair performed. The second is via fetoscopy. These techniques may be an option to standard therapy. Orthopedists monitor growth and development of bones, muscles, and joints. Neurosurgeons perform surgeries at birth and manage complications associated with tethered cord and hydrocephalus. Neurologists treat and evaluate nervous system issues, such as seizure disorders. Urologists to address kidney, bladder, and bowel dysfunction â€" many will need to manage their urinary systems with a program of catheterization. Bowel management programs aimed at improving elimination are also designed. Ophthalmologists evaluate and treat complications of the eyes. Orthotists design and customize various types of assistive technology, including braces, crutches, walkers, and wheelchairs to aid in mobility. As a general rule, the higher the level of the spina bifida defect, the more severe the paralysis, but paralysis does not always occur. Thus, those with low levels may need only short leg braces, whereas those with higher levels do best with a wheelchair, and some may be able to walk unaided. Healthcare professionals working with adults may also be less knowledgeable about spina bifida because it is considered a childhood chronic health condition. The transition itself should be gradual and flexible. A transition plan and aid in identifying adult healthcare professionals are also helpful to include in the transition process. Immigrants from Ireland have a higher incidence of spina bifida than do natives. The reported overall incidence of myelomeningocele in the British Isles was 2. Research[edit] â€" Fetal surgical techniques using animal models were first developed at the University of California, San Francisco by Michael R. Scott Adzick and research colleagues. The MMC-like defect was surgically created at 75 days of gestation term to days by a lumbo-sacral laminectomy. Approximately 3 weeks after creation of the defect a reversed latissimus dorsi flap was used to cover the exposed neural placode and the animals were delivered by cesarean section just prior term. Human MMC-like lesions with similar neurological deficit were found in the control newborn lambs. In contrast, animals that underwent closure had near-normal neurological function and well-preserved cytoarchitecture of the covered spinal cord on histopathological examination. Despite mild paraparesis , they were able to stand, walk, perform demanding motor test and demonstrated no signs of incontinence. Furthermore, sensory function of the hind limbs was present clinically and confirmed electrophysiologically. Further studies showed that this model, when combined with a lumbar spinal cord myelotomy leads to the hindbrain herniation characteristic of the Chiari II malformation and that in utero surgery restores normal hindbrain anatomy by stopping the leak of cerebrospinal fluid through the myelomeningocele lesion. Four cases were performed before stopping the procedure - two of the four fetuses died. The exposed fetal spinal cord is covered in layers with surrounding fetal tissue at mid-gestation 19â€"25 weeks to protect it from further damage caused by prolonged exposure to amniotic fluid. Between and , Dr. Fetal surgery after 25 weeks has not shown benefit in subsequent studies. This conclusion requires a value judgment on the relative value of fetal and maternal outcomes on which opinion is still divided. During pregnancy, all the fetuses in the trial had hindbrain herniation. However, at age 12 months, one-third 36 percent of the infants in the prenatal surgery group no longer had any evidence of hindbrain herniation, compared to only 4 percent in the postnatal surgery group. This approach has been

evaluated by independent authors of a controlled study which showed some benefit in survivors, [85] but others are more skeptical. Compared to the open fetal surgery technique, fetoscopic repair of myelomeningocele results in far less surgical trauma to the mother, as large incisions of her abdomen and uterus are not required. In contrast, the initial punctures have a diameter of 1. As a result, thinning of the uterine wall or dehiscence which have been among the most worriesome and criticized complications after the open operative approach do not occur following minimally invasive fetoscopic closure of spina bifida aperta. There is no need for chronic administration of tocolytic agents since postoperative uterine contractions are barely ever observed. In , two papers were published on fifty one patients. The main risk appears to be preterm labour, on average at about 33 weeks.

6: To the Teenage Girl With Spina Bifida: It Gets Better | The Mighty

How Spina Bifida Affects Childhood Childhood can be difficult enough and those growing up with spina bifida will face challenges that healthy individuals may not be able to relate to. While a majority of those with spina bifida perform well in school those that have shunts due to hydrocephalus, water on the brain, may learn at a slower pace.

Where can I get more information? Introduction The human nervous system develops from a small, specialized plate of cells along the back of an embryo called the neural plate. Early in development, the edges of this plate begin to curl up toward each other, creating the neural tubeâ€”a narrow sheath that closes to form the brain and spinal cord of the embryo. As development progresses, the top of the tube becomes the brain and the remainder becomes the spinal cord. It is the most common neural tube defect in the United Statesâ€”affecting 1, to 2, of the more than 4 million babies born in the country each year. An estimated , individuals with spina bifida live in the United States. What are the different types of spina bifida? There are four types of spina bifida: This form of spina bifida, present in percent of the general population, rarely causes disability or symptoms. This form consists of a diverse group of defects in which the spinal cord is marked by malformations of fat, bone, or meninges. In most instances there are few or no symptoms; in others the malformation causes incomplete paralysis with urinary and bowel dysfunction. Some individuals with meningocele may have few or no symptoms while others may experience such symptoms as complete paralysis with bladder and bowel dysfunction. The impairment may be so severe that the affected individual is unable to walk and may have bladder and bowel dysfunction. The exact cause of spina bifida remains a mystery. No one knows what disrupts complete closure of the neural tube, causing this malformation to develop. Scientists suspect the factors that cause spina bifida are multiple: Prenatal vitamins typically contain folic acid as well as other vitamins. The symptoms of spina bifida vary from person to person, depending on the type and level of involvement. Closed neural tube defects are often recognized early in life due to an abnormal tuft or clump of hair or a small dimple or birthmark on the skin at the site of the spinal malformation. Meningocele and myelomeningocele generally involve a fluid-filled sacâ€”visible on the backâ€”protruding from the spinal canal. In meningocele, the sac may be covered by a thin layer of skin. In most cases of myelomeningocele, there is no layer of skin covering the sac and an area of abnormally developed spinal cord tissue is usually exposed. Complications of spina bifida can range from minor physical problems with little functional impairment to severe physical and mental disabilities. It is important to note, however, that most people with spina bifida are of normal intelligence. All nerves located below the malformation are affected to some degree. Therefore, the higher the malformation occurs on the back, the greater the amount of nerve damage and loss of muscle function and sensation. In addition to abnormal sensation and paralysis, another neurological complication associated with spina bifida is Chiari II malformationâ€”a condition common in children with myelomeningoceleâ€”in which the brain stem and the cerebellum hindbrain protrude downward into the spinal canal or neck area. This condition can lead to compression of the spinal cord and cause a variety of symptoms including difficulties with feeding, swallowing, and breathing control; choking; and changes in upper arm function stiffness, weakness. Cerebrospinal fluid is a clear liquid that surrounds the brain and spinal cord. The buildup of fluid puts damaging pressure on these structures. Hydrocephalus is commonly treated by surgically implanting a shuntâ€”a hollow tubeâ€”in the brain to drain the excess fluid into the abdomen. Some newborns with myelomeningocele may develop meningitis, an infection in the meninges. Meningitis may cause brain injury and can be life-threatening. Children with both myelomeningocele and hydrocephalus may have learning disabilities, including difficulty paying attention, problems with language and reading comprehension, and trouble learning math. Additional problems such as latex allergies, skin problems, gastrointestinal conditions, and depression may occur as children with spina bifida get older. In most cases, spina bifida is diagnosed prenatally, or before birth. However, some mild cases may go unnoticed until after birth postnatal. Very mild forms spinal bifida occulta , in which there are no symptoms, may never be detected. Prenatal Diagnosis The most common screening methods used to look for spina bifida during pregnancy are second trimester weeks of

gestation maternal serum alpha fetoprotein MSAFP screening and fetal ultrasound. The MSAFP test, however, is not specific for spina bifida and requires correct gestational dates to be most accurate; it cannot definitively determine that there is a problem with the fetus. If a high level of AFP is detected, the doctor may request additional testing, such as an ultrasound or amniocentesis to help determine the cause. The second trimester MSAFP screen described above may be performed alone or as part of a larger, multiple-marker screen. Multiple-marker screens look not only for neural tube defects, but also for other birth defects, including Down syndrome and other chromosomal abnormalities. First trimester screens for chromosomal abnormalities also exist but signs of spina bifida are not evident until the second trimester when the MSAFP screening is performed. Amniocentesisâ€"an exam in which the doctor removes samples of fluid from the amniotic sac that surrounds the fetusâ€"may also be used to diagnose spina bifida. Although amniocentesis cannot reveal the severity of spina bifida, finding high levels of AFP and other proteins may indicate that the disorder is present. Postnatal Diagnosis Mild cases of spina bifida occulta, closed not diagnosed during prenatal testing may be detected postnatally by plain film X-ray examination. Individuals with the more severe forms of spina bifida often have muscle weakness in their feet, hips, and legs that result in deformities that may be present at birth. Doctors may use magnetic resonance imaging MRI or a computed tomography CT scan to get a clearer view of the spinal cord and vertebrae. There is no cure for spina bifida. The nerve tissue that is damaged cannot be repaired, nor can function be restored to the damaged nerves. Treatment depends on the type and severity of the disorder. Generally, children with the mildest form need no treatment, although some may require surgery as they grow. The key early priorities for treating myelomeningocele are to prevent infection from developing in the exposed nerves and tissue through the spinal defect, and to protect the exposed nerves and structures from additional trauma. Typically, a child born with spina bifida will have surgery to close the defect and minimize the risk of infection or further trauma within the first few days of life. Selected medical centers continue to perform fetal surgery for treatment of myelomeningocele through a National Institutes of Health experimental protocol Management of Myelomeningocele Study, or MOMS. Although the procedure cannot restore lost neurological function, it may prevent additional loss from occurring. The surgery is considered experimental and there are risks to the fetus as well as to the mother. The major risks to the fetus are those that might occur if the surgery stimulates premature delivery, such as organ immaturity, brain hemorrhage, and death. Risks to the mother include infection, blood loss leading to the need for transfusion, gestational diabetes, and weight gain due to bed rest. Still, the benefits of fetal surgery are promising, and include less exposure of the vulnerable spinal nerve tissue and bone to the intrauterine environment, in particular the amniotic fluid, which is considered toxic. This condition can cause loss of muscle function to the legs, as well as changes in bowel and bladder function. Early surgery on a tethered spinal cord may allow the child to return to their baseline level of functioning and prevent further neurological deterioration. Some children will need subsequent surgeries to manage problems with the feet, hips, or spine. Individuals with hydrocephalus generally will require additional surgeries to replace the shunt, which can be outgrown or become clogged or infected. Some individuals with spina bifida require assistive devices such as braces, crutches, or wheelchairs. The location of the malformation on the spine often indicates the type of assistive devices needed. Children with a defect high on the spine will have more extensive paralysis and will often require a wheelchair, while those with a defect lower on the spine may be able to use crutches, leg braces, or walkers. Beginning special exercises for the legs and feet at an early age may help prepare the child for walking with those braces or crutches when he or she is older. Treatment for bladder and bowel problems typically begins soon after birth, and may include bladder catheterizations and bowel management regimens. Folic acid, also called folate, is an important vitamin in the development of a healthy fetus. Although taking this vitamin cannot guarantee having a healthy baby, it can help. Recent studies have shown that by adding folic acid to their diets, women of childbearing age significantly reduce the risk of having a child with a neural tube defect, such as spina bifida. Therefore, it is recommended that all women of childbearing age consume micrograms of folic acid daily. Foods high in folic acid include dark green vegetables, egg yolks, and some fruits. Many foodsâ€"such as some breakfast cereals, enriched breads, flours, pastas, rice, and other grain productsâ€"are now fortified with folic acid. Many multivitamins contain the recommended dosage of folic acid as well. Women who already

have a child with spina bifida, who have spina bifida themselves, or who have already had a pregnancy affected by any neural tube defect are at greater risk of having another child with spina bifida or another neural tube defect; times the risk to the general population. These women may benefit from taking a higher daily dose of folic acid before they consider becoming pregnant. Children with spina bifida can lead active lives. Prognosis, activity, and participation depend on the number and severity of abnormalities and associated personal and environmental factors. Most children with the disorder have normal intelligence and can walk, often with assistive devices. If learning problems develop, appropriate educational interventions are helpful. In one study supported by NINDS, scientists are looking at the hereditary basis of neural tube defects. The goal of this research is to find the genetic factors that make some children more susceptible to neural tube defects than others. Lessons learned from this research will fill in gaps of knowledge about the causes of neural tube defects and may lead to ways to prevent these disorders. These researchers are also studying gene expression during the process of neural tube closure, which will provide information on the human nervous system during development. In addition, NINDS-supported scientists are working to identify, characterize, and evaluate genes for neural tube defects. The goal is to understand the genetics of neural tube closure, and to develop information that will translate into improved clinical care, treatment, and genetic counseling. Other scientists are studying genetic risk factors for spina bifida, especially those that diminish or lessen the function of folic acid in the mother during pregnancy, possibly leading to spina bifida in the fetus. This study will shed light on how folic acid prevents spina bifida and may lead to improved forms of folate supplements. NINDS also supports and conducts a wide range of basic research studies to understand how the brain and nervous system develop. These studies contribute to a greater understanding of neural tube defects, such as spina bifida, and offer hope for new avenues of treatment for and prevention of these disorders as well as other birth defects.

7: Spina Bifida Association of Kentucky, Inc. : Programs & Services : Growing Up with Spina Bifida

Linnea Winters is a very bright, outgoing third grader, with interests that might seem pretty typical for an average 9-year-old. She loves to read books, enjoys riding her bike and scooter, and playing basketball, and has recently started violin lessons.

She likes to go swimming, play with her dog, and have friends over. Like you, Andrea is interested in many things and can do a lot of stuff. Andrea has spina bifida say: What Is Spina Bifida? Someone born with spina bifida has an opening in the spine. A healthy spine is closed to protect the spinal cord, a bundle of nerves that sends messages back and forth between your brain and the rest of your body. The messages tell your muscles to move so you can kick a soccer ball or pick up a pencil. The messages also tell you about sensations on your skin , so you know to pull your hand away from a hot pot. When a baby is growing inside its mother, the spine and spinal cord are developing. When this happens, a baby is born with spina bifida, a term that means "split or open spine. Usually when your brain says "kick the ball," the nerves of your spinal cord carry that message that tells your leg to kick. These messages may not be able to get through if a person has spina bifida. The person may have weakness or may not be able to move their muscles the way other people do. This is called paralysis say: One kind of spina bifida can go unnoticed. With spina bifida occulta say: There may be some problems with the spine, or there may be no problems at all. Another type of spina bifida is called meningocele say: This involves the meninges, the membranes that cover the brain and spinal cord. Meningocele is the name used when just the meninges â€" no nerves â€" push through the opening in the vertebrae the bones of the spine. The meninges form a fluid-filled sac that is usually covered with skin. The brain and the spinal cord are normal and a person with a meningocele usually has no problems. Sometimes surgery is needed to repair the meningocele and prevent an infection called meningitis. When most people talk about spina bifida, though, they mean myelomeningocele say: This sac contains nerves and part of the spinal cord. About 1 in 1, babies born in the United States has this type of spina bifida. The amount of paralysis will vary, depending on where the opening is on the back. The lower down the back the opening is, the fewer nerves are affected and the less paralysis there is. To help them get around, kids might use crutches, leg braces, or wheelchairs. Andrea, our dancer, was born with an opening in her lower back, just below her waist. She can move her legs but not her feet and ankles. Her skin has feeling only down to her knees. When Andrea was younger she walked with braces and crutches, but now she uses a wheelchair. Like many other kids with myelomeningocele, Andrea also has hydrocephalus say: Some people with spina bifida may have learning problems, but most have normal intelligence. Most kids with spina bifida have some problems with their bowels and bladder. No one is really sure why some kids are born with spina bifida, but doctors and scientists have found some possible reasons. FOLE-ik acid is very important, especially when a baby is growing inside its mother. Folic acid is one of the B vitamins found in foods like broccoli, spinach, egg yolks, and oranges. Luckily, special vitamins containing folic acid are available for pregnant women. A woman who has a high fever early in her pregnancy also may be at higher risk of having a baby who has spina bifida. Scientists are also studying the roles that genes , certain chemicals, and medicines might play in causing spina bifida. What Do Doctors Do? From the moment Andrea was born, doctors have been an important part of her life. When she was just a few hours old, she had her first surgery. Doctors gently pushed her spinal cord back inside her body through the opening on her back, and then closed the opening. When she was 2 days old, the doctors put in a shunt, a device that drains the extra fluid in the brain. Since then, Andrea has had several operations, mostly to replace her shunt. In addition to surgery to keep her shunt working, a kid with spina bifida might need surgery on the feet, hips, or spine. Kids like Andrea also need checkups a couple of times a year and may see a team of medical people. This team may include pediatricians, orthopedists, surgeons, physical therapists, and occupational therapists. They want to help the person to be healthy and as independent as possible. But for most kids, it means taking extra care of their bodies and paying attention if something seems wrong.

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8: Growing Up With Spina Bifida | FPG Child Development Institute

The Spina Bifida Association Parents ListServ External bring people together online to discuss topics such as parenting a child with spina bifida and growing up with spina bifida. National Resource Center External Get information and find clinics or health care providers who are experts on spina bifida.

Linnea Winters, age 9, Spina Bifida Linnea Winters is a very bright, outgoing third grader, with interests that might seem pretty typical for an average 9-year-old. She loves to read books, enjoys riding her bike and scooter, and playing basketball, and has recently started violin lessons. Linnea has a lot of fun, despite the fact that she is living with a physical condition that challenges her every day. It is because of her good nature, tenacity and the support of her family and neurosurgeon, Monica Wehby, MD, that she has been able to live as normal a life as possible. Linnea was born on June 9, , with spina bifida, hydrocephalus and club feet. Brenda and her husband, Phil, went for genetic counseling prior to her first pregnancy because Brenda had a brother who died from a neural tube defect just shortly after his birth. They were told that there was just a 1 to 2 percent risk of having a baby with this birth defect. Their firstborn child, Ethan, was fine. Brenda took folic acid for three months prior to and throughout her pregnancy, a preventative measure that is recommended for women of childbearing age. The second time around, Spina bifida occurs during the third and fourth weeks of pregnancy when a portion of the fetal spinal cord fails to properly close. As a result, the child is born with a part of the spinal cord exposed on the back. Although scientists believe that genetic and environmental factors may act together to cause spina bifida, 95 percent of babies with spina bifida are born to parents with no family history. About 80 to 90 percent of children with spina bifida are born with or develop hydrocephalus. Hydrocephalus is a condition in which excess cerebrospinal fluid builds up within the ventricles fluid-containing cavities of the brain and may increase pressure within the head. Linnea has had two shunt revisions, at age 7 months and age 4," said Dr. At age 5, Linnea underwent surgery for tethered spinal cord. At birth, the spinal cord is normally located opposite the disc between the first and second lumbar vertebrae in the upper part of the lower back. In a baby with spina bifida, the spinal cord is still attached to the surrounding skin, preventing it from ascending normally, so the spinal cord is low-lying or tethered. Although the skin is separated and closed at birth, the spinal cord stays in the same location after the closure. As the child continues to grow, the spinal cord can become stretched, causing damage and interfering with the blood supply to the spinal cord, which can lead to a variety of physical problems. Things are not always easy for Linnea, her parents or her older brother, Ethan, who is I told her that I was sad too, but that I loved her and was glad that she was my daughter. I told her that being sad did not change anything; she still had to take her medicine or have surgery because life goes on," recalled Brenda. Linnea wears ankle-foot orthotics, as do many children with spina bifida, but she is remarkably coordinated. When Linnea expresses disappointment about not being as fast as the other kids in gym class or on the playground, I tell her that I am glad that she does these things anyway, and that this is a miracle that we should be thankful for," said Brenda. Linnea has faced her fears and shared details about her condition with her class. They say they accept me for who I am and think I am just the same as they are," said Linnea. Fortunately, with proper medical care, many children with spina bifida can lead active and productive lives. With recent advancements in medical care for these children, the outlook continues to improve. Women of childbearing age can reduce their risk of having a child with spina bifida by taking micrograms mcg of folic acid every day, whether they are planning a pregnancy or not. Research has shown that if all women of childbearing age took a multivitamin with the B-vitamin folic acid, the risk of neural tube defects could be reduced by up to 70 percent.

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9: Personal Stories | Spina Bifida and Hydrocephalus

Spina bifida, which literally means "cleft spine," is characterized by the incomplete development of the brain, spinal cord, and/or meninges (the protective covering around the brain and spinal cord). It is the most common neural tube defect in the United Statesâ€"affecting 1, to 2, of.

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