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SPINA BIFIDA FACT SHEET

Spina Bifida or “open spine” is a neural tube birth defect that affects the development of the spinal cord, its membrane (lining), the spinal nerves and the backbone. It is the most common permanently disabling birth defect – ***the most complex birth defect compatible with life.***

Spina bifida affects three in 10,000 births in the United States and currently an estimated 130,000 people in the United States are currently living with spina bifida; in Georgia, there are 1,800 children and adults with spina bifida.

There are 60 million women at risk of having a baby born with spina bifida. Everyday, an average of eight babies are affected by spina bifida or a similar birth defect of the brain and spine. Each year, about 3,000 pregnancies are affected by these birth defects.

Every unborn infant’s spine is open when it first forms, but normally closes during the first month following conception. In spina bifida, the backbone never properly closes. Forms of spina bifida range from having no open portion of the spine and no nerve damage to an extrusion of the spinal meninges poking through the back with resulting minor disabilities through severe disabilities with nerve damage.

Major personal issues for individuals with spina bifida include mobility (requiring the use of crutches or wheelchairs) and bowel and bladder control.

While individuals with spina bifida may have other medical problems, such as hydrocephalus, many are also challenged with psychosocial problems and learning disabilities.

The life expectancy for this population has changed from adolescence in the 60’s to a normal life expectancy today.

Research has shown that 400 mcg of folic acid taken daily prior to conception and in the first three months of pregnancy can reduce the risk of having a baby with spina bifida by as much as 70%.

The Spina Bifida Association of Georgia (SBAG) has watched the population of youth born in the early 80’s grow up, go to college and now begin to enter the workforce; these “emerging young adults” present a whole new challenge to the healthcare community.

Even through their college years, most of these young people have been treated by pediatricians – in pediatric hospitals and clinics. However, they are now beyond the age to be seen by pediatric providers. Many (particularly those fortunate to be treated in the metro Atlanta area where there is a concentration of pediatric specialists because of two pediatric hospitals) have received care that considers “the whole child” – as one medical problem, particularly spina bifida, can greatly influence the function and balance of other systems, thus their overall health, along with their emotional and “living health” and quality of life.

Obviously, even for adults, the best care is usually found in a greater metro area (like Atlanta) which has the benefit of teaching hospitals at universities where more specialized medicine is practiced and medical understanding is more advanced. However, an undetermined number of these young adults are not residents of Atlanta and treatment in Atlanta may result in a full day off from work and become a negative factor in the eyes of employers who may hire these young adults.

Statewide, there is an inadequate healthcare capacity available for this growing population of emerging young adults; accepted protocols for the treatment of adults with spina bifida do not exist.

The Spina Bifida Association of Georgia (SBAG) is a 501(c)(3) non-profit organization whose mission is to promote the achievement of full potential for persons born with spina bifida while emphasizing the prevention of this birth defect.

As an advocate for patient standards of care, SBAG has helped train healthcare workers on procedures and treatments of this very specialized birth defect. *Guidelines for Spina Bifida Health Care Services Throughout the Lifespan* was recently published by the national Spina Bifida Association and will be distributed to all parents and adults with spina bifida. SBAG plans to distribute this guidebook to all physicians who care for this population, along with OB/GYNs, neonatologists, hospitals and school nurses.

Currently, SBAG is formulating plans to launch an aggressive spina bifida prevention campaign to combat rising spina bifida births in Georgia, particularly in the Hispanic communities.

For additional information on spina bifida and its prevention, contact:

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