Medical Records
The project investigators will review the participant’s medical records and school records to extract data that will help to understand how the participant is functioning.

Benefits
A participant will receive an evaluation of his/her ability to learn and behavioral adjustment. The results will be discussed with the caregiver and can be made available to other professionals or the school upon request. The family will receive a written report summarizing the results of the assessment. Any problems identified on the MRI will be reported to the caregiver with the written report from a radiologist sent to the participant’s physician.

Risks
A participant and/or the caregiver may get tired or feel nervous during the testing or completion of forms. If this occurs, they will not be pressured to respond but may take a break before continuing, or may discontinue at any time.

The MRI procedure is non-invasive and does not involve any exposure to radiation. Blood drawn from the participant and parents for genetic studies may leave a small bruise and discoloration at the location of the needle insertion. Whenever possible, the staff will coordinate the blood drawn for the genetic studies with other blood drawing in order to prevent numerous punctures.

Confidentiality
The project investigators will protect the confidentiality associated study participation. The participant’s test results will be coded anonymously and strict confidentiality regarding the participant’s test performance will be maintained. Records will be kept in locked cabinets and coded using an identifier.

Compensation
There will be no charge for any of the evaluations performed in this project, including the MRI. There is financial compensation for each visit to cover expenses such as transportation and parking.

The SANDI Project Staff
MAIN STUDY
Dr. Jack M. Fletcher, Principal Investigator
Amy Hampson, Coordinator
Rosalva McPherson, Psychometrician
Reyna Velázquez, Medical and Research Assistant
Catherine Watkins, Researcher

GENETIC STUDY
Dr. Hope Northrup, Principal Investigator

EARLY LEARNING STUDY
Dr. Susan Landry, Principal Investigator
Dr. Heather Taylor, Co-Investigator

If you have any questions about or wish to participate in the SANDI Project, please contact the Coordinator, Amy Hampson at 832-842-2007
THE SANDI PROJECT is a five year, five million dollar collaborative research project between the University of Houston, Hospital for Sick Children in Toronto, the University of Texas Health Science Center—Houston, Baylor College of Medicine, Texas Children’s Hospital, and Shriners’ Hospital for Children.

**Project Goals**
The project has two goals:

- to identify key outcomes (skills and abilities, academic and vocational achievement, behavioral and social adjustment) in children, adolescents, and adults with Spina Bifida Meningomyelocele (SBMM).
- to relate the difference in outcome to genetic and patterns, medical history, brain development, and social and educational environments.

To address these goals, we plan to:

- evaluate skills and abilities, academic and vocational achievement, and behavioral and social adjustment
- conduct magnetic resonance imaging (MRI) of the brain
- analyze genetic material (DNA)

To date, more than 500 families have participated in this study. We hope to enroll 500 more families in this phase of the project to related difference in outcome to genetic and patterns, medical history, brain development, and social and educational environments.

**Core Assessment**
The purpose of the core assessment is to collect information about basic abilities, learning skills, social adjustment, and medical history. Some of this information is obtained from direct testing with children, adolescents, and young adults with SBMM. While the assessment is being conducted, the parent or caregiver will be asked to complete forms that ask about the participant’s behavior and environment.

**MRI Study**
A participant enrolled in the project will be asked to undergo a Magnetic Resonance Imaging (MRI) scan of the brain. MRI is a non-invasive method for providing very clear images of the inside of the brain. The MRI scan will be performed at the University of Texas Medical School. We will not require any individual to undergo sedation in order to obtain the MRI scan.

**Genetics Study**
All participants and their families will be asked to participate in a study to determine genetic factors which cause Spina Bifida Meningomyelocele. By discovering genes which cause SBMM, we hope to devise strategies for prevention and/or treatment. Participation in the genetics study involves donation of a blood or saliva sample from the patient, both parents, and possibly additional family members. We will study the genetic material (DNA) from the families to identify genes that cause SBMM. Because we know that there are probably multiple genes which play a role in causing SB, the task is difficult. We need participation from as many families as possible.

**Early Learning Study**
The Early Learning Study aims to understand the development of skills and abilities of children with SBMM who were earlier studied as infants and toddlers. We now plan to study these children’s skills and early learning abilities at 7, 8, and 9 years of age.

**Neurocognitive Study**
The Neurocognitive Study aims to understand attention, memory, visual perception, information processing, and language comprehension skills in children, adolescents, and adults with spina bifida.

**Who is eligible?**
- Infants and young children birth — 7 years
- Children, young adolescents and adults with SBMM, 7 – 50+ years
- Spina Bifida Meningomyelocele
- No other genetic syndromes
- No other neural tube defects