A History of Compassionate and Innovative Care

Children's Memorial's highly regarded Division of Neurosurgery, headed by Tadanori Tomita, MD, Yeager Professor of Pediatric Neurosurgery, is making important strides in treatment and care for children affected by hydrocephalus. Our program offers an interdisciplinary team of medical professionals, rehabilitation specialists and educational experts who are committed to improving outcomes for patients with all forms of hydrocephalus. This team of experts has built a reputation as one of the region's leading programs for the diagnosis, treatment and ongoing management of hydrocephalus. Each year, we care for more than 1,500 children on an inpatient basis and record as many as 5,000 outpatient visits related to the ongoing management of hydrocephalus. In addition, the division annually performs between 500 and 600 hydrocephalus-related surgical procedures, including shunt placements and revisions. We continue to achieve excellent clinical results and to record a high return ratio of satisfied patients.

With decades of clinical and research experience, the Division of Neurosurgery has the clinical population and the investigative agenda needed to extend the boundaries of care for children with hydrocephalus. As powerful new tools and technologies become available, they must be used effectively to advance medical knowledge and clinical practice in the field of pediatric neurosurgery. The opportunity to improve treatment of hydrocephalus has never been more within our reach. Philanthropy will offer Dr. Tomita and the other physician-researchers within the Division of Neurosurgery the opportunity to bring about advances and opportunities in the field that were never before possible by fulfilling the following research priorities:

Development of Enhanced Shunt Technology

Hydrocephalus is a neurological condition that occurs when there is an abnormal accumulation of cerebrospinal fluid (CSF) inside each of the four ventricles of the brain. When the circulation or absorption of CSF is blocked, or a large amount of fluid is produced, the volume of the brain becomes excessively larger then normal. Surgical interventions are the primary treatment of hydrocephalus. This is done by the placement of a ventricular shunt, which drains the CSF into areas of the body where it can be reabsorbed.

While Children's Memorial has made great strides in treating even the most challenging forms of hydrocephalus through the use of shunts, more work is needed to ensure superior care and optimal outcomes for all children with this condition. A major concern of our physicians for many years has been the ongoing quality of life of children who have undergone shunt placement, due primarily to the high rate of shunt-related infections, malfunctions and other causes necessitating ongoing surgical revisions. This situation underscores the need for better shunt technologies.

A top interest for Dr. Tomita is to expand the scope of research surrounding the development of an innovative new servo regulating shunt system, essentially a non-invasive intracranial pressure monitoring device that will adapt to ongoing changes in the brain. Presently, shunt system function is dependent upon the pressure differentials measured in the brain before and immediately after shunt placement, meaning that the shunt valve does not take into account ongoing physiological changes within the brain and open and close in response to those changes. Another limitation of present technology is that intracranial pressure (ICP) monitors are placed in the brain and connected to an outside computer via a wire, requiring the patient to remain bound to the bed for an extended period of time in order to get an accurate read of intracranial pressure.

Working in union with experts in biomedical engineering, either through Northwestern University or the private sector, Dr. Tomita proposes to develop a miniature implantable computer capable of monitoring ICP and regulating the shunt valve according to the ICP status, something that has never before been possible. Once the implantable miniature ICP monitor is available, he will focus on the development of a shunt valve which opens and closes by the signals from the ICP monitor. This unique technology will eliminate the limitations and complications imposed by current shunt systems. The successful attainment of this goal, made possible through the generous support of the One Small Voice Foundation, stands to revolutionize the field of hydrocelphalus care and create greater opportunities for patients everywhere to receive cutting edge treatment.

Clinical Research

The neurosurgery program also strives to improve the level of care for our patients through the continued pursuit of clinical research. Our investigators are currently pursuing a wide range of studies to examine the medical, psycho-social and economic impact of hydrocephalus on children and their families, with a goal of addressing the special needs and quality of life issues facing children at various stages of their lives.

In line with this work, we ask you to consider supporting two components of our clinical research. Our first goal is to establish a database specific to pediatric hydrocephalus, which will allow us to identify the risk factors for the development of slit ventricle syndrome, a condition that can develop in patients who have undergone shunt placement for treatment of hydrocephalus. This condition causes the brain's ventricles to become so small that they are often barely visible on a CT scan or MRI, and often results in repeated hospitalizations related to shunt malfunction symptomatology including chronic headaches, vomiting or other symptoms.

This can be a painful and debilitating condition for a child to endure. Unfortunately, physicians currently are not able to readily detect the onset of slit ventricle syndrome and the illness often goes unexplained. Dr. Tomita's goal is to determine how to better manage this condition and, ultimately, to prevent it altogether. To accomplish this task, he has entrusted the coordination of a prospective clinical study of patients with slit ventricle syndrome to Rudy Kayama, MD, MBA. Dr. Kayama is collecting data on patients in order to pinpoint trends leading up to the onset of slit ventricle syndrome. The hope is that information gained from this study will translate to improved diagnosis and evaluation of this condition, and, consequently, to superior treatment and alternatives to surgery wherever possible.

The second proposed project focuses on Quality of Life among hydrocephalic children. In general, Quality of Life research looks at the scope and severity of complications faced by hydrocephalus patients and the impact these issues have on a child's cognitive and behavioral functioning and social competence. More specifically, patients suffering from hydrocephalus may experience more outward physical disabilities, repeat hospitalizations and neuro-cognitive problems that can affect an individual's independence, employment and educational goals. Under Dr. Tomita's direction, investigator Venkat Sadanand, MD, PhD, is testing a new Quality of Life questionnaire that is designed to assess the progress and concerns of our patients and their families. A total of 100 patients have completed the questionnaire to date. This data instrument will examine the various types of hydrocephalus treated at Children's Memorial and the trends and outcomes associated with each. The hope is to determine the frequency of shunt malfunction associated with certain cases of

hydrocephalus, whether the patient admissions were elective or an emergency, the patient's age at the time of admission, the average length of hospital stay, the symptomatology present at the time of shunt malfunction and the treatment options that have proved to be most favorable. Data from this study will provide sound scientific evidence to help us advocate more effectively for further research that will lead to more successful treatments.

The One Small Voice Foundation's generous support will provide Drs. Kayama and Sadanand with the protected time needed to pursue their respective projects on a full-time basis. Furthermore, these resources will also allow us to offset the costs of a statistician to assist with data analysis. Since Children's Memorial treats a large number of hydrocephalic patients, perhaps the largest number in the nation, both studies are extremely important to improve the quality of life of children with hydrocephalus. Over time, the results of this research could have tremendous significance for our clinical activities, allowing us to modify treatments and improve overall outcomes for patients with all forms of hydrocephalus.

Basic Medical Research

Hydrocephalus is a chronic and debilitating condition that can cause blindness, brain damage and death if not treated. Presently, there is no known way to prevent or cure hydrocephalus. While shunt treatment allows many children diagnosed with the disorder to go on to lead normal lives, there are problems that still remain unsolved in the treatment of hydrocephalus, such as shunt obstruction and infection. All of these issues prompt the need to better understand the origins and biological mechanisms of hydrocephalus in order to perfect new treatments and one day prevent the condition altogether.

Dr. Tomita proposes to partner with neurobiologist Shekhar Mayanil, PhD, to study the basic mechanisms by which genes interact in the early stages of human development to form the central nervous system, and how disruptions in this process can lead to defects. More specifically, they plan to examine the molecular basis of hydrocephalus, focusing on morphogens (proteins that act as transcription factors) and growth factors of the central nervous system during embryonic development. They will also study the growth factors and morphogen profiles of the cerebrospinal fluid found in hydrocephalic patients.

While numerous published research papers have primarily looked for morphological changes (those that control the organized spatial distribution of cells during development) in cases of hydrocephalus, we will be among the first to approach hydrocephalus at molecular genetic level, and investigate whether cytogenetic (chromosomal) manipulations may lead to the condition. Information gained from this work may lead to the discovery of new ways to prevent, detect and treat the abnormalities found in hydrocephalus. Philanthropy is extremely vital to the progress of research and advanced clinical care. It allows us to provide high-caliber physician-scientists like Dr. Mayanil with protected time and income to pursue this promising avenue of research.

Training for New Technologies

Finally, in order to improve the care and outcomes for hydrocephalus patients, we have been increasingly using advanced neuroendoscopic technologies. The neuroendoscope is a useful new tool that enhances visualization during surgery. This technology gives surgeons the ability to look around corners and behind obstructions. While this provides an additional view to the surgeon, the

high magnification also allows good definition of the surrounding structures. With available philanthropic support from the One Small Voice Foundation, Dr. Tomita would like to upgrade the division's current neuroendoscope, and establish a laboratory for training our surgeons and others in the use of this state-of-the art equipment.

Thank You for Your Consideration of this Request

Research is key to unraveling the complexities of hydrocephalus and achieving breakthroughs that can transform children's lives for the better. With support from the One Small Voice Foundation, Dr. Tomita and his colleagues will expand their capacity and knowledge to serve the children who need outstanding neurosurgical care. New therapies emanating from this work may hold the key to a vastly different, and better, future for our patients. With our deepest appreciation, we thank you in advance for your belief in this work and the mission of Children's Memorial Hospital.