

planning for KIDS

A charitable gift planning newsletter for SickKids donors

SickKids®
FOUNDATION

SPRING 2006 NUMBER 15

HEALTHIER CHILDREN. YOUR LEGACY FOR A BETTER WORLD.

Meet Michael

Michael is a bright, cheerful two-year-old boy who was diagnosed with the extremely rare neuromuscular disease Lesch-Nyhan Disease (LND). This disease affects approximately one in 20 million people and causes poor motor control; difficulty with sitting and walking and a compulsion to self injure. There is no known cure for LND.

Michael's mother, Melissa, suspected something was wrong when Michael wasn't reaching early developmental milestones. Eventually, his doctors determined that Michael had LND. The doctors told Michael's parents that if he had not been diagnosed before the age of two, he would have suffered kidney damage.

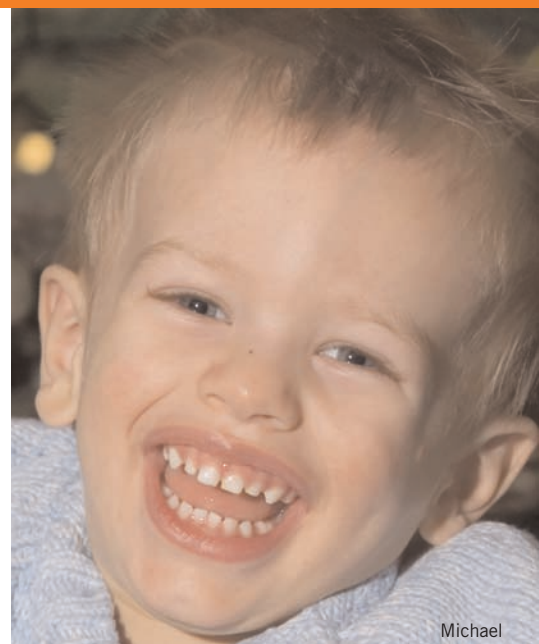
Children with LND face multiple health issues including seizures, kidney stones, increased risk of developing Parkinson's disease and sudden death.

These children have an average life span of 25 years.

Michael visits SickKids every three months and is followed by a medical team led by geneticist Dr. Alan Berzen. Michael's life is filled with medical appointments, blood work, urine testing, physiotherapy and occupational therapy. "When we are at SickKids, he never fusses, he always has a smile on his face and is constantly laughing," says Melissa. At home, Michael, who uses a "stander" to support him when he stands – plays just like any other child would, and enjoys colouring, finger painting and story time.

Melissa and Peter have established the Michael Carl Lesch-Nyhan Disease Research Fund, and are hoping that SickKids will one day find a treatment and cure for this disease. They have created a website, www.themichaelfund.com to educate, raise awareness and money for LND research.

"We try to make Michael's life as normal as we can, and when we do have to go to appointments, we try to make them a happy time, which, with Michael, is pretty easy to do," says Melissa. "My family and I look at Michael not knowing how much time we will have with him, so we make every minute as special and precious as possible. Michael is truly my angel and I would not trade him for the world."



Michael

TUNE IN TO RADIOTHON

With a combined audience of over two million people, Newstalk 1010 CFRB, 97.3 EZ Rock and Mix 99.9 will broadcast live from the hospital's Atrium on April 5, 6 and 7 for The 20th Annual SickKids Radiothon. Patients, families and staff will share their stories of courage and hope at SickKids. Last year, we broke all Radiothon records across North America by raising nearly \$3.2 million in 72 hours.

Thank you, to you, our donors!
Your support makes a real difference to the children we serve.

MIX99.9
FM
More Music • More Variety

97.3 *AM* **EZ Rock**
Today's Soft Rock with 102.5 FM

NEWTALK
1010
CFRB

For more information visit www.sickkidsfoundation.com

SICKKIDS CHARITABLE GIVING FUND

The SickKids Charitable Giving Fund offers a unique opportunity for donors who wish to streamline their giving, while maintaining control, flexibility and involvement with their gifts.

Backed by SickKids Foundation, this new option – also known as a donor advised fund – is available to individuals and corporations wanting to create a lasting charitable legacy.

A donor advised fund is a cost-effective alternative to creating your own ‘private foundation.’ You are able to personalize your gift, advising how you would like your philanthropic dollar to be spent, but at a fraction of the cost of working with a financial institution, while still receiving excellent stewardship of your assets.

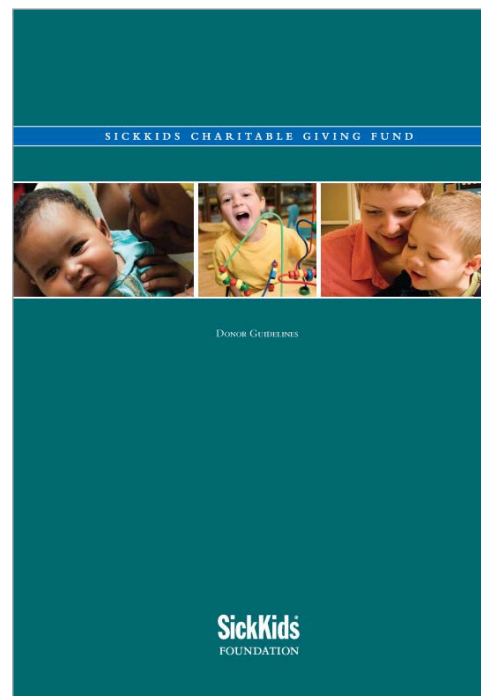
A portion of the annual disbursement from the fund will support SickKids. The remaining amount can be directed to any other registered Canadian charities of your choice. Contributions you make to the fund are officially receipted and the grant-making procedure is simple.

For more information about donor advised funds and maximizing tax advantages through a fund, please contact Angela Murphy via email at givingfund@sickkidsfoundation.com or by phone at 416-813-8260.

The Robert and Naomi Shapero Family Donor Advised Fund

Robert and Naomi Shapero and their four children have always lived in the Greater Toronto Area. Recently, Robert and Naomi wanted to give back to the community, but they wanted to do something more permanent than making annual donations to various charities.

“We were looking for a way to support our favourite charities more strategically and also wanted to find a way to introduce our children to philanthropy and instill the importance of giving back,” says Robert.



To accomplish their goal, Robert and Naomi have decided to establish a donor advised fund at SickKids Charitable Giving Fund. By establishing the Robert and Naomi Shapero Family Donor Advised Fund, the family can make decisions together about what charities they would like to support without the associated costs and cumbersome administrative requirements of a private family foundation.

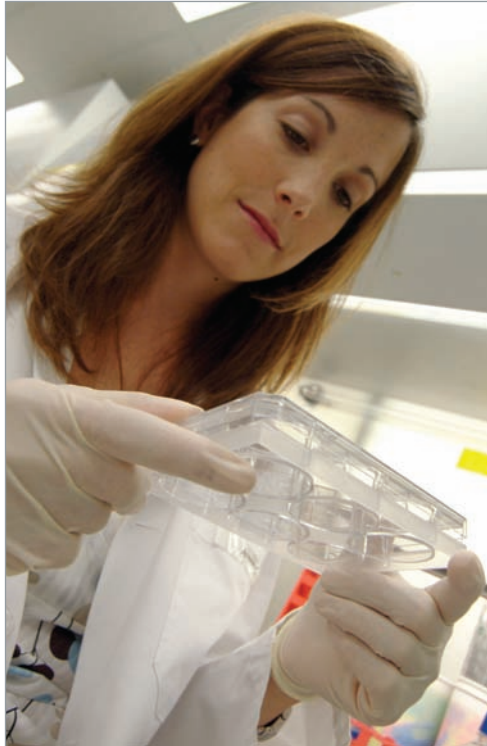
While Robert and Naomi’s children are still quite young, they hope to include them in future granting decisions. As their children grow and develop charitable interests of their own, they can support them through the Robert and Naomi Shapero Family Donor Advised Fund.

Robert sees additional value in the permanence of a donor advised fund. “By creating a culture of philanthropy within our family, we hope that we will be able to impact children’s health and other worthwhile causes during our lifetime and beyond. It is fulfilling to know that our children and grandchildren will be able to carry on this legacy of giving long after we are gone.”

Are you looking to maximize your giving ability?

It is anticipated that the Spring 2006 Budget will result in the elimination of capital gains tax on listed stocks donated to charities. If this new legislation is enacted, you will be able to deduct the full market value of donated securities, regardless of what you paid for them. With these expected tax savings, the actual cost of your gift is less than if you made a cash gift. For more information contact the Gift and Estate Planning Team at 416-813-8271.

Genetics at SickKids



Genetics is the scientific study of genes. Genes provide the instructions that determine our physical characteristics (like eye colour) and also influence how our bodies grow and develop. Genetics is of particular interest in paediatric health care, as 96 per cent of chronic disorders in children have a genetic basis and 71 per cent of conditions that prompt admission to a children's hospital have contributing genetic factors.

Genetics at SickKids is divided into two main categories, clinical and research.

The Division of Clinical and Metabolic Genetics provides diagnosis, management and genetic counselling for individuals and families affected with or at risk for the development of genetic disorders. This group includes physicians,

nurses, dieticians, social workers and genetic counsellors. Together, they see over 3,000 patients each year.

Genetics and Genomic Biology is the program focused on genetic research. Genetic researchers work on the basic fundamental aspects of genes and how they function in diseases. While the clinician's primary role involves direct patient care, the researcher tries to identify the genetic basis of the disease by studying the individual's genetic makeup in relation to the clinical features.

Today, researchers are not just focusing on the treatment of genetic disorders caused by alterations in a single gene, efforts are also being directed into studying more complex and common genetic conditions such as asthma, autism and type-1 diabetes. According to Dr. Johanna Rommens, Program Head and senior scientist in Genetics and Genomic Biology, "the future of genetics will allow not only treatment of genetic disorders but prediction and disease prevention as well."

Cheryl Shuman, Director of Genetic Counselling, notes that genetics at SickKids has earned international respect. "We are committed to providing compassionate and comprehensive care to patients and their families impacted by genetic disorders. Our interdisciplinary team of health-care providers and researchers works collaboratively to enhance the health of children and families both locally and around the world."

Dr. Rommens recognizes SickKids Foundation for its contribution to research at SickKids. "The Foundation routinely invests funds for projects in which the end result is not always clear. Thanks to this effort, many research discoveries have been achieved at SickKids." In 1989, researchers at SickKids discovered the gene responsible for cystic fibrosis.

GENETICS AT THE HOSPITAL FOR SICK CHILDREN

Did you know that...?

- Classical examples of genetic disease include cystic fibrosis and thalassemia. Susceptibility to common childhood diseases such as asthma and diabetes also involve genetic factors.
- Genetic susceptibility is involved in 96 per cent of all chronic disorders of childhood.
- Genetic factors contribute to 71 per cent of all paediatric admissions.
- There are over 5,000 genetic diseases but causal genes have been identified in fewer than half of them.
- Over 1,600 disease genes have been identified and just over 800 diagnostic tests are available. Of those, approximately 200 are available in Ontario.
- The availability of diagnostic testing can significantly impact medical care and help identify high-risk people who may require more intensive screening or early intervention.
- SickKids has been a pioneer in the study of human genetics, particularly in the area of disease gene identification.

Thank you

The Gift and Estate Planning team at SickKids Foundation would like to express our gratitude to the members of our SickKids Legacy Advisors Program. SickKids Foundation recently launched the SickKids Legacy Advisors Program with a goal to partner with top professional advisors across a range of specialties including law, accounting, investments, insurance, wealth management and financial planning. SickKids Legacy Advisors are professionals who share SickKids Foundation's commitment to advancing philanthropy by educating the public on tax-wise and values-based planning.

The exceptional professionals who make up this exclusive group have been an invaluable resource as we aim to provide you, our donors and friends, with the best and most current information regarding your gift and estate planning needs. Members of this group have given their time to attend educational seminars, hospital tours and meetings to learn more about SickKids and how they can contribute to our goal of seeing every child, everywhere healthy.

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If you are seeking gift and estate planning services, we would be delighted to speak with you, or to provide a copy of our SickKids Legacy Advisors Directory. Please contact us at 416-813-8271.

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The information provided is general in nature and not intended to be a substitute for professional legal and financial planning advice. The Foundation encourages donors who are planning a significant donation to seek legal and financial planning advice.

SickKids Foundation respects the privacy of its donors; we do not sell, rent or trade our donor lists. The information we collect is used to process donations, keep our donors informed about the activities of the hospital and Foundation, and ask for their support for our mission to improve children's health. If at any time you wish to be excluded from future contacts, or to discuss our privacy options, call us at 416-813-8271 and we will accommodate your request.

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