

# PLANNING FOR KIDS

SICKKIDS GIFT PLANNING NEWSLETTER

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## Sequencing some very Canadian genes

Our latest research partner at SickKids is a true Canadian. He's Ward the Beaver, and he usually makes his lodge at the Toronto Zoo. His genes, however, came to SickKids (via blood samples), for two important reasons: national pride, and world-leading science.

First, the pride part: SickKids has made a lot of history in its 142 years. We're almost as old as the country we call home. So, to celebrate Canada's 150th birthday, a SickKids-led research team decided to make a little more history. Dr. Stephen Scherer, Dr. Si Lok and their team undertook sequencing the full beaver genome.

Next, the science. When you fund research at SickKids through a gift in your will, you advance the science that will help find answers to conditions that affect kids. So you may be asking, "Why the beaver?" The answer is that most mammal genomes – chimps, humans, and yes, beavers – are roughly the same size. That natural point of comparison made sequencing the beaver genome an ideal exercise to improve research methodology at The Centre for Applied Genetics (TCAG). Says Dr. Scherer, "Using the latest genome sequencing technologies we use to study human genomes, we wanted to develop some new and improved methods to test on the beaver genome, so we could then apply those back to studying human disease."

What's equally important is the *kind* of sequencing they did on Ward.



**Ward the beaver, a genetics pioneer. Sequencing his genome will help SickKids researchers identify mutations in the human genome. Photo courtesy of the Toronto Zoo.**

Dr. Lok compares the usual human sequencing their lab does to piecing together 'a jigsaw puzzle' – but one where you already know what the final picture is, because you have the box. As he says, "This is actually *re*-sequencing." What they're doing with Ward is different – it's called '*de novo*' sequencing. The distinction is important. Says Dr. Lok: "We don't know what the beaver genome looks like. We have to assemble it without knowing the final picture the jigsaw puzzle makes. If we can do this, we can use the same technology and the same approach to identify new mutations in the human genome that we're currently missing."

Identifying these mutations is where the answers to conditions like autism and cancer may lie. By funding research like this through a gift in your will, you're giving answers to families in the future – answers as powerful as "We can use your son's own genes to fight his cancer."

# A gift 30 years in the making

Russell de Souza is here today because of SickKids. The mother of this McMaster University medical sciences professor, Rosemarie de Souza, is certain of it. Which makes her the best person to tell his story. This is from the beautiful note she wrote to us about her family's connection to SickKids:

Russ was our seventh attempt at being parents (I had 6 miscarriages!). He was born in November, 1974, at Mount Sinai hospital (where I had spent 3 months on bed rest), at 6 months gestation, weighing 2.5 lbs. He was immediately wheeled underground to SickKids. He seemed to have done well the first few days – then reality set in. He had to have excessive amounts of oxygen, and later developed RLP (retrolental fibroplasia) and was sightless. He regained his sight much later. He had an ileostomy, but because he was so tiny, could not be operated on again until he was over a year old. He spent the better part of his first year (and even had his 1st birthday) at SickKids.

We visited daily. The team dedicated to his care – and I mean “dedicated” – not only took care of him like he was their own, but comforted us and encouraged us on days when there seemed to have been no hope at all. They kept us informed of his ups and downs, and our nightly phone calls for updates were handled with honesty and compassion.

Over many days and nights, we came to respect the



At SickKids, 30 years ago: the de Souzas with Russell, and Colman's mom.

work of the staff and nurses.

We knew gifted surgeons, with determination and special skills, would perform the delicate procedures this fragile infant would need.

We thought: “Other people’s donations and countless prayers gave us our son – now it is our turn.”

The family have been donors for over 30 years. If anyone has anything to add, it’s her husband, Colman, who still calls Rosemarie “my wife, my darling wife, my bride”. He echoes her sentiments: “We have only one son. We believe that if it wasn’t for Sick Kids, we wouldn’t even have this one child. So we felt that Sick Kids certainly merits being remembered in our will.”

**“Other people’s donations and countless prayers gave us our son – now it is our turn.”**



The de Souzas today. From left: Russ and his wife Celine; Rosemarie; Russ and Celine's son Ethan; Colman de Souza.

# The girl with 'glass bones'

Grace Turnbull is a little girl surrounded by love. She has to be – because Grace has 'glass bones'. That's the term her school principal used to help Grace's classmates understand her osteogenesis imperfecta, a genetic condition that makes her bones break under the slightest pressure – and it stuck.

When you leave a gift to SickKids in your will, you're supporting the hospital that's supported Grace her whole life. Which, for Grace, hasn't been easy. Her parents, Liz and David Turnbull, knew she had special needs when they adopted her, but it wasn't until they got home, and to SickKids, that Grace's condition was diagnosed. They couldn't even pick her up at first, so they carried her on a duvet cover.

Grace has had surgeries to implant rods in her leg



Grace's classmates at Pineview Public School in Georgetown, Ontario support Grace. They made this snowflake, the symbol of her condition.

bones, strengthening them so she can do things every kid loves, like walking through fresh, crunchy snow. Still, it's tough on Grace, and her mom. As Liz says, "I've lost track of how many fractures she's had." Liz visited Grace's school, and had the kids make paintings of Grace's special bones, which they assembled into a snowflake, the symbol of osteogenesis imperfecta. At school, as well as at home, Grace is surrounded by love.



Grace Turnbull, SickKids osteogenesis imperfecta patient, standing tall.

When you meet Grace, the first thing you note is the sparkle in her eyes. "She loves to paint. She loves to play with Lego, and outdoors. She's very much about nature,"

## "She loves to paint. She loves to play outdoors."

says her mom. And she visits SickKids regularly – for treatment that helps her live her life, so that her spirit never breaks.

## Did you know? Saving on taxes can be easier than you think.

### **Include SickKids as a beneficiary on your life insurance policy, RRSP/RRIF, TFSA.**

It's an easy way to maximize your gift and receive a charitable tax credit. Changing your beneficiary does not have to be documented in your will, so the process is quick and convenient.

### **Offset estate taxes.**

Leaving a gift in your will provides a charitable tax receipt to your estate to offset any taxes owing at death. Remember, if you have left a gift in your will, please let us know – so we can thank and recognize you through the JP Bickell Society.

### **Eliminate capital gains tax on donated securities.**

By transferring appreciated securities directly from your brokerage account into SickKids' account, you eliminate any capital gains tax. Your tax receipt will be issued based on the fair market value on the day shares are received.

# SickKids VS

In October 2016, the world heard SickKids new rallying cry for the first time. It was a shift in attitude. It was a shift in tone. It proclaimed what SickKids has always done – bring together the world's best medical minds to fight for the health of every child – in a way that had never been done. We proclaimed that it's SickKids VS the greatest challenges in child health.

We launched VS for two reasons: to jolt anyone sitting on the sidelines into joining our fight, and to remind those who've already rallied to our cause – people like you – of the magnitude of our fight. And how much your support is still needed. As you know, the needs of the hospital grow each year, as the challenges we face grow more complex. Which is why we always look to our community for support.

Remembering SickKids in your will can be part of that. It is an act that's generous, powerful, and surprisingly simple. It allows you to leave a larger gift than would be possible during your lifetime, it produces a charitable tax receipt that can lower or even eliminate estate taxes, and it keeps you in the fight. Which is a terrific legacy.

Thank you for considering a gift in your will. It's you and SickKids VS the greatest challenges in child health.

Best wishes for spring and summer,  
The Gift and Estate Planning Team

## Bequest information

SickKids Foundation is the hospital's parallel charity which raises money, performs estate administration, and manages endowments on behalf of The Hospital for Sick Children (SickKids).

Do your estate plans include SickKids Foundation? Let us know! We are grateful for your gift and would love to say thank you. You may also wish to become part of our J.P. Bickell Society, which honours members at an annual luncheon, and places their names on our Donor Wall of Honour.

If you plan to make a bequest, the name you should include in your will is:

**The Hospital for Sick Children Foundation**

## Privacy

SickKids Foundation respects the privacy of its donors. Please read our full privacy policy at [www.sickkidsfoundation.com](http://www.sickkidsfoundation.com).

## About Planning for Kids

Planning for Kids is a charitable gift planning newsletter published twice a year by SickKids Foundation. 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.

## Share with us

We invite you to share your comments and ideas with us. If you have an idea for a story or would like to make a general comment or suggestion about the contents of the newsletter, please call 416-813-8271 or send an email to [gift.planning@sickkidsfoundation.com](mailto:gift.planning@sickkidsfoundation.com).

## About the cover photo

Evie was six months old when SickKids doctors discovered a tumour in her brain. Six years later – after many rounds of chemotherapy and four surgeries – Evie continues to fight the tumour, with the SickKids team on her side.



# SickKids®

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