

# McMaster Children's Hospital Twenty years of caring and innovation



hen the doctors tell you that your child is sick and needs help, the words seem impossible to believe. Many parents and families who come to McMaster Children's Hospital (MCH) never thought they would need the specialized care offered at a children's hospital, but when that day arrived they were incredibly thankful that MCH was there to care for their child and for their whole family.



#### Caring for our future, one child at a time

Health care professionals, educators and researchers at McMaster Children's Hospital (MCH) in Hamilton, Ontario are committed to caring for the unique needs of every child and family. The family-centred care philosophy at MCH is based on a foundation of collaboration and communication, with caregivers being responsive to the needs and wishes of patients and families. This approach encourages children to participate in their own care, and for parents and family members to be active members of the care team while in hospital and at home.

Established in 1989, McMaster Children's Hospital is a member of the Hamilton Health

Sciences family of health care facilities. Over the past 20 years, MCH has grown in leaps and bounds – from 68 to 132 inpatient beds and from 22 to 42 outpatient clinics. MCH encompasses the whole continuum of care, providing a seamless system from diagnosis to treatment to rehabilitation to ongoing care in the community.

McMaster Children's Hospital is one of the busiest children's hospitals in Ontario. It is home to the second largest neonatal intensive care unit and the third largest child and youth mental health unit in the country. MCH has produced research and treatment standards that are the cornerstone of autism care internationally. It is also a world-

renowned centre for research and treatment of

childhood obesity.

McMaster Children's Hospital has a rich and collaborative relationship with McMaster University and together they have created the unique and innovative McMaster Child Health Research Institute, an institute that examines the impact of child health and wellness challenges over the lifespan. The strong partnership between MCH and McMaster University has also been integral in the development of two internationally-respected organizations, CanChild Centre for Childhood Disability Research and the Offord Centre for Child Studies.

### Growing from within

#### Experienced pediatric surgeon now leads McMaster Children's Hospital

According to McMaster Children's Hospital (MCH) patient 10-year-old Riley Berryman, the new president of MCH has magical hands. Dr. Peter Fitzgerald developed a one-of-a-kind surgery specifically engineered for Riley to help repair his enlarged bowel, giving him the chance to be a happy-go-lucky kid again.

Along with magical hands, Dr. Peter Fitzgerald is a distinguished surgeon with a national and international reputation for his innovative work and leadership in minimal access (keyhole) surgery and reconstructive chest wall surgery. He has been integral in establishing the minimal access pediatric surgery program at MCH.

Dr. Fitzgerald knows the pediatric health care system inside out from both frontline and administrative perspectives. In his capacity as the medical director of MCH for the last five years and chief of pediatric surgery, he has unique insight into the complexity of running a children's hospital that is committed to providing the highest quality of care for every child and family, every day, without exception.

Dr. Fitzgerald describes the "phenomenal" growth of McMaster Children's Hospital into one of the foremost children's hospitals in the country as exciting, and he looks forward to both the opportunities and



challenges that lie ahead. But while MCH's programs and facilities may be growing, Dr. Fitzgerald is adamant that his team will continue to provide the personalized care that is the hospital's hallmark.

"Every patient and family that we see at MCH has a unique situation and a great deal of collaboration, research and thought go into treating each individual case," said Dr. Fitzgerald.

Dr. Fitzgerald, a professor of pediatric surgery at McMaster University's Michael G. DeGroote School of Medicine, has made significant contributions to undergraduate surgical education, particularly in the development of evaluation standards. He believes in getting back to the basics of providing good quality care and is instilling that belief in the next generation of health care professionals. He is also committed to opening avenues of recruitment worldwide to bring the best and brightest talent in pediatric care to McMaster Children's Hospital.

"Dr. Fitzgerald is a visionary, decisive leader," said Murray Martin, President & CEO, Hamilton Health Sciences. "He is respected by his colleagues and highly regarded by his patients as a wonderful doctor. Dr. Fitzgerald is the right choice to lead MCH into the future."

Heroes come in all sizes – MCH patient Riley Berryman and Dr. Peter Fitzgerald, new president of MCH



Making children's mental health 'top of mind' - PG 2

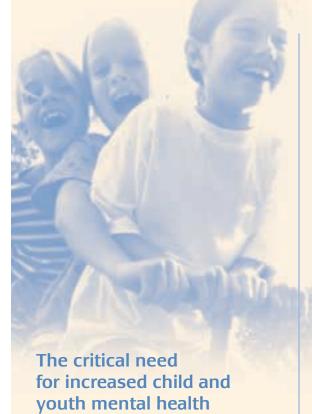
Selena and Sarah's stories... – **PG 3** 

Handle with care: Pediatric patients in good hands with first-class physicians – PG 6

Obesity: A weighty issue for the future health of Canadian children – PG 9

### Making children's mental health 'top of mind'

McMaster Children's Hospital opens one of Canada's largest inpatient units



• 1 in 5 children have a mental health problem

services in Canada

- 1 in 10 children have aggressive behaviour problems
- 1 in 3 children experience physical or sexual abuse
- 1 in 20 teenagers are clinically depressed
- 1 in 20 children start school without the skills needed to learn
- 1 in 200 children are diagnosed with autism

Child and youth mental health problems pose a tremendous challenge for the children, teens and families affected. These problems are very common, and the issues they create can last long into adulthood.

For society, child and youth mental health problems also consume a vast amount of financial and human

resources. The team at McMaster Children's Hospital understands the critical need to invest in early identification and treatment for children and youth with mental health challenges.

The Child and Youth Mental Health Program at MCH is affiliated with the Faculty of Health Sciences and Department of Psychiatry and Behavioural Neurosciences at McMaster University, and McMaster Children's Hospitals' worldrenowned Offord Centre for Child Studies. These centres are all leaders in child and adolescent development, wellness promotion and mental health care, with many of their practices being adopted world-wide.

Children and youth with serious mental health problems can already access a wide range of outpatient services at McMaster Children's Hospital. The Child and Youth Mental Health Program offers numerous services, including consultation, assessment and treatment groups for children and youth suffering with a variety of difficulties, including depression, generalized anxiety disorder, obsessive compulsive disorder and social phobia.

The program also partners with many community services across south central Ontario to help ensure that children and youth have timely, coordinated access to specialized, ongoing care.

Responding to the increasing need in our society, the Child and Youth Mental Health Program is growing at an

incredible pace. The RBC Child and Youth Mental Health inpatient unit will include 22 beds - 16 for youth and six for children. This unit will open this summer along with an associated day hospital and outreach service. These services will provide seamless care for children and youth up to age 18. This unit will represent the third largest

"It is our responsibility

tomorrow's society

The late Dr. David "Dan" Offord,

founding director of the Offord Centre for

Child Studies, was one of the world's

leading experts in child development

will benefit."

- Dan Offord

and child psychiatry.

to ensure bright futures

for today's children so that

child and youth mental health inpatient unit in the country and signals MCH's commitment to addressing this critical issue facing our children and society today.

The design of this purposebuilt unit was conceived through a lengthy and thoughtful functional planning process that had patients at the forefront of all decisionmaking. It will include a recreational lounge, educational learning areas, as well as a full kitchen and dining facilities.

Under the direction of Dr. Rhodri Evans, the Medical Director for the Child and Youth Mental Health Program, many highly skilled health care professionals have been recruited,

including four child and adolescent psychiatrists who are also Assistant Professors in the Department of Psychiatry and Behavioural Neurosciences at McMaster University.

As many as 450 children and youth will receive care in the unit each year with the focus of admission being to stabilize the patients, determine a diagnosis and develop a plan to help them get better. This new unit complements the continuum of care provided at MCH, and adds to existing and growing outpatient and community-based services.

The Child and Youth Mental Health Program team is committed to providing exemplary family-centred care, based on evidence and best practices. It is filling a major service gap in mental health care for children and youth in south central Ontario.

More than 150,000 children and families are cared for each year at McMaster Children's Hospital.

# Carol Solis never thought her daughter, Selena, would be one of them.

#### Selena's story...

"Selena can

walk and talk,

do anything,

Very soon."

sing and dance.

She can and will

at 110 per cent.

- Lines from the song

to her daughter, Selena.

Carol Solis sang

It was Thanksgiving weekend in 2007 and Carol Solis and her daughter Selena were enjoying themselves at a party in Burlington with family and friends. They had so much to be thankful for. In 2000, Carol adopted Selena from China as a baby and her daughter had grown into a vivacious, talented, creative and fun-loving little girl.

It was at the party when Carol noticed Selena slumped over at the top of the stairs. When she called to her daughter, Selena's words were jumbled and her right side was completely limp.

Selena was rushed to McMaster Children's Hospital (MCH) by ambulance.

"When we arrived at the hospital, I remember being told that Selena was in critical condition and the doctors weren't sure she was going to make it," said Carol. "It was a parent's worst nightmare."

Tests revealed that Selena had suffered a hemorrhagic stroke, which means bleeding occurs in the brain and damages the surrounding tissue. This type of stroke is rare, affecting only one in 100,000 children, yet strokes are among the top 10 causes of childhood death. If Selena did survive, it was likely she would have severe brain damage.

Dr. Thorsteinn Gunnarsson, a pediatric neurosurgeon at MCH, performed brain surgery on Selena and removed a piece of her skull that would allow her brain to swell. He also inserted a drain to relieve the pressure on her brain. The operation saved Selena's life.

Five days after being rushed to the hospital, Selena opened her eyes. Although Selena was out of the woods,

her recovery had only just begun. The stroke left Selena unable to sit up, talk, walk or even move her arms.

To inspire Selena, Carol made up a song for her and sang it to her dozens of times a day. They set goals together and Carol insisted that only positive comments be made in Selena's presence.

"Her progress was significantly faster than anyone would have imagined and those of us who worked with her were amazed," said Helena Pelletier, a Registered

Dietitian at MCH. "Of all the children and families I have worked with over the past 10 years, Selena and her mom inspired me the most. Their positive outlook and commitment to achieving their goals were surely a huge part of her amazing progress."

Working with a team of health care professionals at MCH, Selena was gradually able to hold her head up, stand and then walk. She relearned how to pick things up and feed herself. And she regained her speech. "I remember seeing her one morning and hearing her say, 'I love you, Mommy'," said Carol. "It was incredible."

There is very little evidence left of the ordeal that Selena went through. Although

covered by her hair, she has a scar that extends from her ear, around the back of her head and up to her forehead. Her right arm is slightly bent and it takes effort for her to straighten it. And although she is able to run, she still has a slight limp. But Selena is determined that the rest of her road to recovery will be short. "Because I'm like a speed rocket," said Selena. "And right now I feel super, duper great."

and brightest health care professionals to tackle complicated childhood illnesses

Access to the best

# Sarah's story...



Sarah Byars' beautiful mane of red hair, glowing smile and bubbly personality conceal the many and varied health challenges this bright little girl has faced in her short life.

At only 11 years of age she can pronounce the names of all three of her diseases perfectly and is quick to help adults who stumble over them.

Sarah has a combination of Osteogenesis Imperfecta (brittle bones disease), Von Willebrands disease (hemophilia) and Crohn's disease (a gastrointestinal disease.)

She has broken countless bones and has to be very careful not to cut herself for fear of bleeding too much. On top of that, she faces the hurdles and challenges that come along with managing Crohn's disease every day.

Sarah came to McMaster Children's Hospital from her home in Guelph, Ontario when she was five years old. This is when she first met Dr. Robert Issenman, head of Pediatric Gastroenterology.

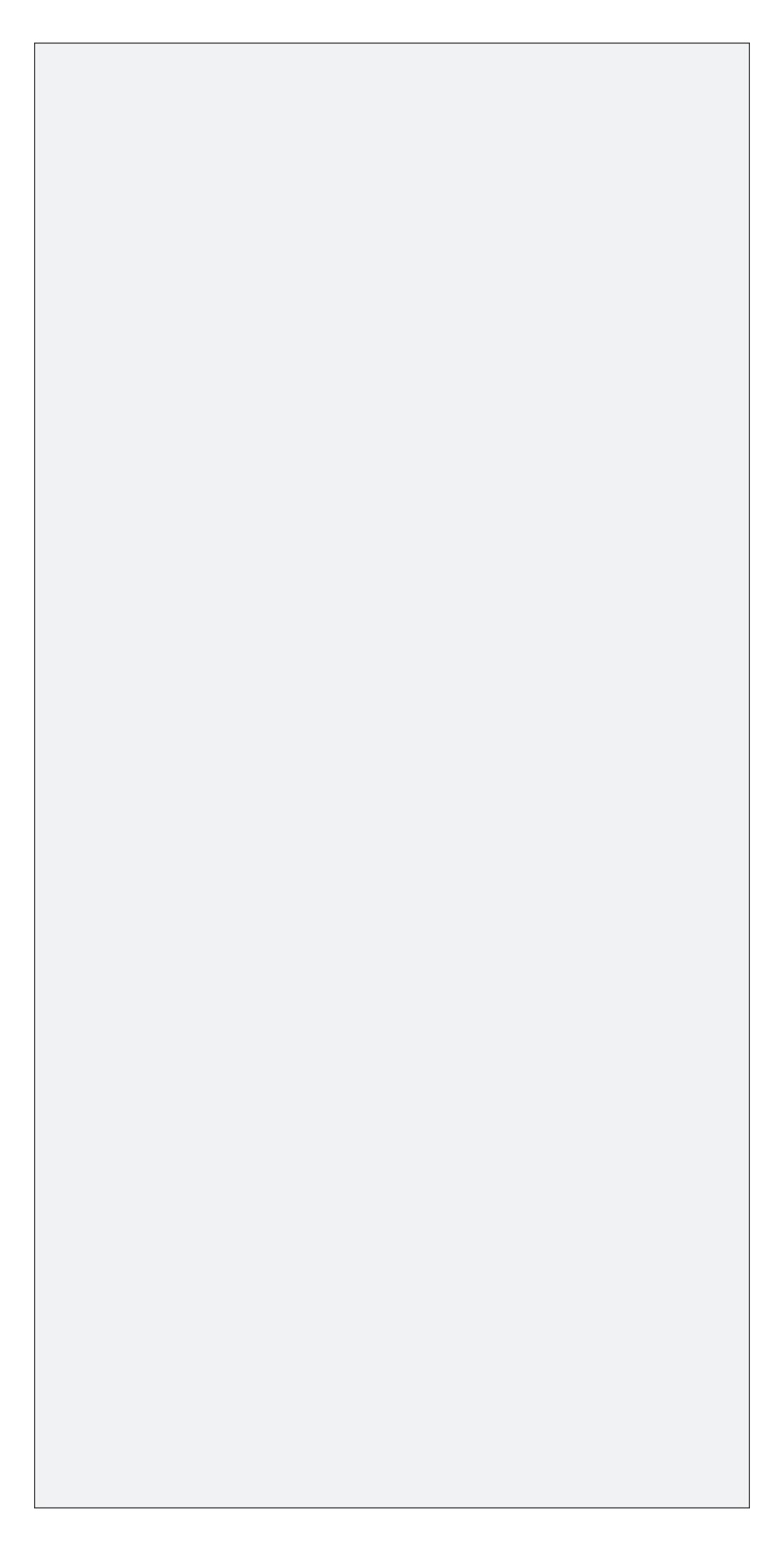
Dr. Issenman has been coordinating Sarah's care at McMaster Children's Hospital – working in collaboration with other pediatric specialists and multi-disciplinary teams – with the goal of helping Sarah and her family achieve the best quality of life possible.

Sarah is likely the only person in North America with this combination of diseases. But, this is not a challenge she or her health care team shrink away from – quite the contrary. The health care team at McMaster Children's Hospital is inspired by Sarah's courage and determination and uses that energy to fuel new and innovative approaches for her care.

When Karen Guse, Sarah's mother, first met Dr. Issenman, he took hold of both of her hands and said, "You are here to look after Sarah and I am here to worry about her."

True to his word,
Dr. Issenman has been doing
that ever since, providing
comfort, reassurance and great
care to Sarah and her family.





# Keeping it real: Simulator program brings lifesaving education to life

Imagine it's your first week of residency in pediatrics at a world-renowned children's hospital. There are 20 minutes left on your shift and you will have made it through without a major event. You are about to breathe a sigh of relief when you hear a page overhead – Code Blue – Ward 3B - Room 17- STAT. Your heart stops, you break into a cold sweat as you realize that this isn't a practice run, this is the real thing. Someone's heart has stopped beating and their life is hanging in the balance and it is your job to save them. What's even scarier - it's a child.

The high-fidelity simulator program at McMaster Children's Hospital (MCH) is a life-saving educational tool that prepares physicians and health care professionals for this exact moment.

McMaster Children's Hospital is home to the only pediatric training program of this kind in Ontario and one of very few in Canada. In order to advance its two key missions of education and patient safety, MCH has brought simulation from the classroom into the clinical setting and trained a multidisciplinary team of instructors.

The two simulators are modeled after a seven-year-old boy and a six-month-old infant. The simulators breathe, blink, cry, and respond to medication orders that are put into the computer program. More importantly, sophisticated computer software allows the simulator to interact and change depending on the actions of the medical team. Monitors can be attached to the simulators, just as they would be to a real child or infant, to display vital signs such as blood pressure and heart rhythms.

Doctors, nurses, respiratory therapists and medical students are able to simulate a variety of clinical scenarios, from an infant with a cold, to a child having a cardiac arrest from an unknown cause. The health care team is able to make crucial medical decisions and practice life-saving techniques.

Continuous training and practice through the simulation program stimulate best-practice educational modules, excellence in clinical practice, and optimum patient outcomes.

Research shows that the more often health care professionals deal with particular cases, the better the



Simulation training in action – The pediatric critical care team resuscitates one of the simulators in the PCCU. Real equipment is being used to maintain the airway, listen to breath sounds and pulses.

outcomes. There is growing evidence that high-fidelity simulation is an effective way of exposing a higher volume of patient cases to medical professionals.

The simulators also help learners experience a more life-like experience than with past training methods. "You can see it in the learners' eyes. You can see the moment when they realize that if they don't do the right things for this patient, there could be some serious consequences," said Dr. Lennox Huang, Interim Chief of Pediatrics at McMaster Children's Hospital and Medical Director for the simulator program. "In the past we would train with plastic dummies that required a great deal of imagination on the part of the learner and the instructor, and now we have this innovative new program and tools that bring the scenarios to life."

Simulated scenarios also provide staff with an opportunity to apply MCH's family-centred care philosophy, which encourages families and caregivers to be participants in their child's care.

"Our learners and staff automatically incorporate parents in the scenario - whether it's something as simple as giving intravenous fluids or more acute involvement," said Dianne Norman, Clinical Outreach Specialist. "We are also committed to sharing this philosophy with our peers and partners in the community."



#### Reaching beyond everyday practice

The capabilities of the simulator program are constantly evolving. The highfidelity simulators that are modeled after real children and are programmed to reproduce physiological responses, are now being used to increase the safety of patients at McMaster Children's Hospital. Whenever a new piece of equipment is introduced to the children's hospital, it is first trialed with the simulator in the area where it will be used. The simulators are then used to train and educate staff on the new equipment. The simulators have also been used to test and implement new hospital policies and protocols.



## Handle with care: Pediatric patients in good hand





he choices that we make today have a direct and sometimes profound impact on the realities of tomorrow. Nowhere is this more evident than when we are making choices about our children's health care and well-being. The doctors at McMaster Children's Hospital are among the best and the brightest in the world. They form a rich tapestry of experience, knowledge and relationships that together provide the world-class care patients and families receive at MCH every day. The team shares the goal of helping each child reach his or her own potential. With this commitment directing their decision-making, our future is in very good hands.





Dr. Ronald Barr **Pediatric Oncologist** 

Dr. Ronald Barr is a world-renowned pediatric cancer specialist. He has established a multidisciplinary team of health professionals to care for children with cancer and blood disorders. The team works collaboratively to respond to the needs of children and their families and is a model for familycentered care used by institutions around the world. Dr. Barr's commitment to succession planning in pediatric cancer care has been integral in building a regional, national and international legacy of patient care, research and education in pediatric hematology/oncology.

Dr. Barr's research delves into the essential question of why adolescents and young adults have not experienced the same increase in positive outcomes for cancer care as children and older adults have over the last number of years. His research has contributed greatly to helping close the gap for this age group to ensure that they are receiving the best and most appropriate care possible.

Dr. Barr has always been a strong advocate for children's health, in particular, seeking to address inequities within the Ontario health care system for children with cancer. He, together with his colleagues at the other four academic children's health care centres in Ontario, formed the Pediatric Oncology Group of Ontario (POGO) and Dr. Barr is the current president. A grassroots organization, POGO has grown to attain status as an official consultant/ advisory group to the Ministry of Health and Long-Term Care for children's cancer care in Ontario. Dr. Barr has also devoted countless hours to projects that have made a true impact on the delivery of care to children with cancer in developing countries around the world.



Dr. Rhodri Evans **Child and Adolescent Psychiatrist** 

Dr. Rhodri (Rhod) Evans is the Medical Director of the Child and Youth Mental Health Program at McMaster Children's Hospital and an Associate Professor in the Departments of Psychiatry and Behavioural Neurosciences and Pediatrics at McMaster University.

Dr. Evans is an accomplished child and adolescent psychiatrist who has been in practice for more than 30 years, 20 of them as a specialist. After training in the UK and working at the IWK Health Centre in Halifax, Nova Scotia, Dr. Evans joined the MCH team in 2004.

His key areas of interest and specialty are in community child and youth mental health, and forensic (legal) issues in child and adolescent psychiatry.

Dr. Evans' vision for child and youth mental health care is based on the knowledge that mental disorders are common in childhood and adolescence and that an organized, coordinated, comprehensive service delivery system is necessary to attempt to meet this growing need. Dr. Evans believes wholeheartedly that mental health disorders in childhood and adolescence are the responsibility of many stakeholders in health, education, the community and the private sector, and there needs to be a collaborative approach by society to address this incredible issue for our children and youth.

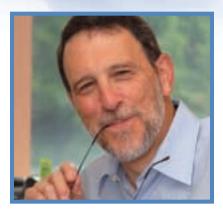


Dr. Sheila Singh **Pediatric Neurosurgeon** 

One to watch in Canada's 'Top 40 Under  $40^{\text{TM}}$ ,' Dr. Sheila Singh, a world-class pediatric neurosurgeon, holds the Canada Research Chair in Human Cancer Stem Cell Biology. Dr. Singh's research activities are focused on brain tumor initiating cells. Her two main goals are to develop therapies that will target these abnormal cells that may be responsible for the formation of brain tumours, and to provide insight into patient prognosis and outcomes. Through this important research, Dr. Singh is making great strides in understanding brain tumours, which are a leading cause of cancer deaths in children, and a type of cancer that is very difficult to cure.

"There is wonderful infrastructure in place at McMaster Children's Hospital and McMaster University," said Dr. Singh. "And McMaster University has a huge drug discovery program, so I am in a perfect environment to begin targeting the tumour-initiating cells, once we find out what makes a neural stem cell into a cancer stem cell."

Dr. Singh feels that her dual roles as a practicing pediatric neurosurgeon and a scientist complement one another because the tumours she sees in the operating room stimulate and foster ideas she takes to the lab.



Dr. Peter Rosenbaum **Developmental Pediatrician** 

One of the first formally trained developmental pediatricians in Canada, Dr. Peter Rosenbaum has earned an international reputation as the leading clinical and health services researcher in his field. An original 2001 Canada Research Chair holder (in Childhood Disability, Dissemination and Mentoring), and a Professor of Pediatrics at McMaster University, Dr. Rosenbaum has dedicated his career to advancing the field of developmental disability as a research and academic discipline.

Dr. Rosenbaum is committed to ensuring that research is effectively translated into practice. In 1989, Dr. Rosenbaum, with his colleague Dr. Mary Law, co-founded the CanChild Centre for Childhood Disability Research at McMaster University, an award-winning multidisciplinary research program that aims to advance the quality of health services for the benefit of society – specifically those members of society who have, or are raising a child or youth with, a childhood disability.

Dr. Rosenbaum is the inaugural Director of the McMaster Child Health Research Institute (MCHRI), and holds the Scotiabank Chair in Child Health Research. The institute addresses the needs of children with complicated lives and their families within a life-course perspective. The Institute is comprised of a consortium of several Faculties and Departments across McMaster University and McMaster Children's Hospital.

#### s with first-class physicians



Dr. Charles Cunningham Psychologist

Dr. Charles Cunningham has been involved in the development of many aspects of the world-class care provided by McMaster Children's Hospital and Hamilton Health Sciences over the last 30 years through his various roles as a psychologist, the Clinical Director of the Community Educational Service, and a Professor in the Department of Psychiatry and Behavioural Neurosciences at McMaster University, where he holds the Jack Laidlaw Chair in Patient-Centred Health Care.

With an international reputation for developing and conducting innovative research that examines the utilization, cost-effectiveness, and outcome of interventions for children with mental health problems, Dr. Cunningham's ground-breaking work has left an indelible mark on the lives of many patients and families around the world. He has also been involved in the development and evaluation of programs to combat some of today's most pressing issues for children and families including bullying and violence in schools. Dr. Cunningham's work spans the globe and his practices and research have been adopted as far away as Sweden, Japan and across North America.

Dr. Cunningham is a core member of the internationally-renowned Offord Centre for Child Studies and is integral in advancing its position as a leader in improving the life quality and life opportunities of the one in five Canadian children and youth who suffer from serious social and emotional problems. Dr. Cunningham has also paved the way for the development of the Patient-centred Service Research Unit at Hamilton Health Sciences.



Drs. Sheri Findlay (left) and Christina Grant Adolescent Medicine

Drs. Sheri Findlay and Christina Grant are a dynamic and dedicated pair of adolescent medicine physicians.

Dr. Findlay is the head of the Division of Adolescent Medicine and the Medical Director of the McMaster Children's Hospital Eating Disorder Program.

Drs. Findlay and Grant infuse ingenuity and energy into their clinical practice, which involves caring for children and teens with eating disorders.

The Eating Disorder Program at MCH is unique and ground-breaking in its approach as it uses family-based treatment for teens with anorexia nervosa. Families are actively involved in helping their children return to a healthy status.

Dr. Grant has also invested much of her time in creating a very innovative and important Transition Clinic for youth with Type 1 Diabetes as they move to the adult system. The clinic supports patients through any challenges related to their growth and development and also helps to educate these patients around safe sex practices, birth control and offers a harm risk reduction approach to substance abuse.



Dr. Mark Tarnopolsky Neurometabolic and Neuromuscular Expert

Dr. Mark Tarnopolsky is a world leader in researching and treating neuromuscular and neurometabolic disorders. Dr. Tarnopolsky has a passion for helping children and adults with these disorders, including muscular dystrophy, Lou Gehrig's disease and Parkinsons disease.

Dr. Tarnopolsky is the clinical and research director of the Neuromuscular and Neurometabolic Centre at McMaster Children's Hospital and Hamilton Health Sciences which includes the Corkins/Lammert Family Clinic for Mitochondrial Medicine and Research. He is also a Professor of Pediatrics and Medicine at McMaster University.

Patients at the neuromuscular and neurometabolic centre receive a range of services including molecular and metabolic testing and rehabilitation for their long-term care.

Dr. Tarnopolsky also evaluates nutrition, exercise and pharmacological strategies to enhance muscle function in health and disease.



Dr. Anthony Chan Pediatric Hematologist / Oncologist

Dr. Chan is the medical director for pediatric cancer care at MCH and is a leading expert in the field of pediatric thrombosis and stroke. He shares that expertise through a telephone hotline. Health care professionals from all over the world call the line and Dr. Chan consults with them free of charge.

He is also the pediatric director of a unique, combined Pediatric and Adult Hemophilia Treatment Centre at Hamilton Health Sciences – a model for the seamless transition of chronic patients from pediatric to adult care. In addition, Dr. Chan is involved in a twinning program with Serbia through the World Federation of Hemophilia.

Dr. Chan is a Career Investigator funded by the Heart and Stroke Foundation of Canada. His research has led to the creation of a novel anticoagulant (a medication that prevents the blood from clotting) that has the potential to better control coagulation in babies undergoing cardiopulmonary bypass. Dr. Chan has developed a number of inventions that have led to many patents and products that help patients everywhere. Dr. Chan also participates in designing clinical trials, such as treatment studies in children with stroke through the International Pediatric Stroke Study.



**Dr. Ronit Mesterman Pediatric Neurologist** 

Dr. Ronit Mesterman is the Medical Director of the Developmental Pediatrics & Rehabilitation Program and the Autism Spectrum Disorders Services. As a Pediatric Neurologist she is committed to caring for the whole child from their acute to long-term care needs. Her dual training in pediatric neurology and developmental pediatrics allows her to use a neuro-developmental approach when assessing children with complex conditions.

Dr. Mesterman believes that developmental disorders and neurological conditions have common underlying causes and finds great value in treating the two conditions together. When Dr. Mesterman was recruited to McMaster Children's Hospital five years ago, her goal was to work in both areas to bridge the care provided and spark new collaborations resulting in optimal care for patients.

As a developmental pediatrician, Dr. Mesterman treats children with a wide-variety of conditions such as complex motor problems, cognitive deficits, autism, cerebral palsy, genetic syndromes such as Down syndrome, complex behavioural problems and other rare, neuro-developmental conditions. The other element of complexity to the care she provides is that she must take into consideration the growth and development of the patients and the adjustments that must be made to their care over time.

Developmental conditions are common, with 10-15 per cent of all children having problems affecting their development. There is a great need for increased health care professionals and resources in the area of developmental pediatrics. Dr. Mesterman is a dedicated advocate for increased provisions for this area to ensure timely and high quality care for patients and families.



Dr. Helene Flageole Pediatric Surgeon

Dr. Helene Flageole joined the team at McMaster Children's Hospital in September of 2007, after being in practice for more than 11 years at McGill University and Montreal Children's Hospital.

Dr. Flageole is a pediatric surgeon at MCH as well as a professor in the Departments of Surgery and Pediatrics at McMaster University

While in Montreal, Dr. Flageole developed a clinical interest and expertise in prenatal diagnosis and treatment of congenital anomalies; kidney transplantation; and diaphragmatic pacing techniques (much like a heart pacemaker, it sends messages to the diaphragm which drives the lungs causing the patient to breathe.) She has also completed extensive research examining both the causes and prenatal treatment of birth defects that lead to abnormalities of the diaphragm. Given the strength of the clinical research work happening at MCH, Dr. Flageole has shifted her focus from basic research in the laboratory to research in the clinical setting.

Dr. Flageole is very active with the Royal College of Physicians and Surgeons of Canada, as the program director in pediatric general surgery and the chief examiner for pediatric general surgery.





# Everyone knows a child with a complicated life

The McMaster Child Health

Research Institute is poised

to transform the future

for children whose lives

are complicated by illness

or disability.

Some children have lives that have been complicated by illness or disability, such as cancer, diabetes, depression, anxiety, obesity or cerebral palsy. Other children may have a physical or learning disability, or social or behavioural problems.

For most children and their families, these complications don't disappear when they reach adulthood. Even when identified and addressed early, these childhood conditions often impact child and family health and well-being throughout life.

Researchers at the McMaster Child Health Research Institute (MCHRI) want to change that. They want every child to reach his or her full potential and have meaningful lives, even when those lives are complicated by challenges of health or development.

The MCHRI fuses the pediatric expertise of McMaster Children's Hospital with the thriving research innovations at McMaster University. The Institute is the first of its kind in Canada and unique in its innovative approach to lifelong health. Rather than looking at treatments for isolated conditions, our researchers are exploring the deeper connections between childhood disability and illness and long-term health.

Over the years, researchers at McMaster Children's Hospital and

McMaster University have made great strides in better understanding autism, obesity, childhood cancer and neuromuscular diseases. Major advances have also been made in treating children with motor disabilities such as cerebral palsy, preventing child

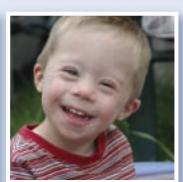
> maltreatment, and understanding the wellbeing of parents who have children with cancer. But there is more to be done, and this will be achieved by bringing these researchers together through the MCHRI.

Many chronic diseases and disabilities share common elements. They all affect how a child develops, interacts with their family and loved ones, participates in the community and achieves success in school. By working together and sharing knowledge, researchers at the MCHRI will discover new perspectives, leading to new ways of helping children with complicated lives and their families thrive.

Perhaps one of the most exciting aspects of the MCHRI is the national and global impact its research and knowledge translation activities will have. The research findings generated at the MCHRI will help children and families far beyond the borders of our community. The goal of the Institute is to spread this new knowledge far and wide, so that the lessons learned here in Hamilton can create hope and healthier futures for children all around the world.









# Obesity: A weighty issue for the future health of Canadian children

There are often social costs for children who are obese. But obesity can also lead to



other severe health consequences. A recent study at the Children's Exercise & Nutrition Centre at McMaster Children's Hospital (MCH) found that 50 per cent of the children coming to the clinic had hypertension or high levels of cholesterol and triglycerides -

all risk factors for cardiovascular disease. Children as young as seven years of age were found to be pre-diabetic.

Twenty-six per cent of Canadian children are considered overweight or obese. That number is continuing to grow at an alarming rate.

The effects of the obesity epidemic will likely continue well into the future. "Twenty years down the road, today's children and teenagers will have joined the workforce, and will be dealing with the burden of diabetes, heart disease and other chronic illnesses resulting from being overweight in their childhood," said Dr. Katherine Morrison, a pediatric endocrinologist. "The social and health implications alone are worrisome; never mind the economic impact."

Dr. Morrison is one of the founding partners of the McMaster Child Health

Research Institute (MCHRI) and a researcher studying childhood obesity. She is the principal investigator for the DECCO study (Determinants of Change in Childhood Obesity), in partnership with the Population Health Research Institute at Hamilton Health Sciences and McMaster University. It is a three-year study funded by the Canadian Institutes for Health Research and the Heart and Stroke Foundation of Canada.

#### Today's generation of children may be the first to live shorter lives than their parents.

The children participating in the DECCO study were given a blood test that checked their glucose and insulin levels before and after drinking a high sugar

The early results of the DECCO study were startling. Tests revealed that one in four of the children had pre-diabetes. Without key changes to their lifestyles, these children were at increased risk of developing type 2 diabetes, a chronic disease that often leads to early onset blindness, heart disease, kidney disease, nerve damage and a myriad of other lifealtering health consequences.

It was clear to Dr. Morrison and her colleagues that there was a need for an intensified approach to help these children change their lifestyles now, before further health complications arose. And so, the Obesity At-Risk (OAR) Clinic at McMaster Children's Hospital was born.

The OAR clinic sees children who are

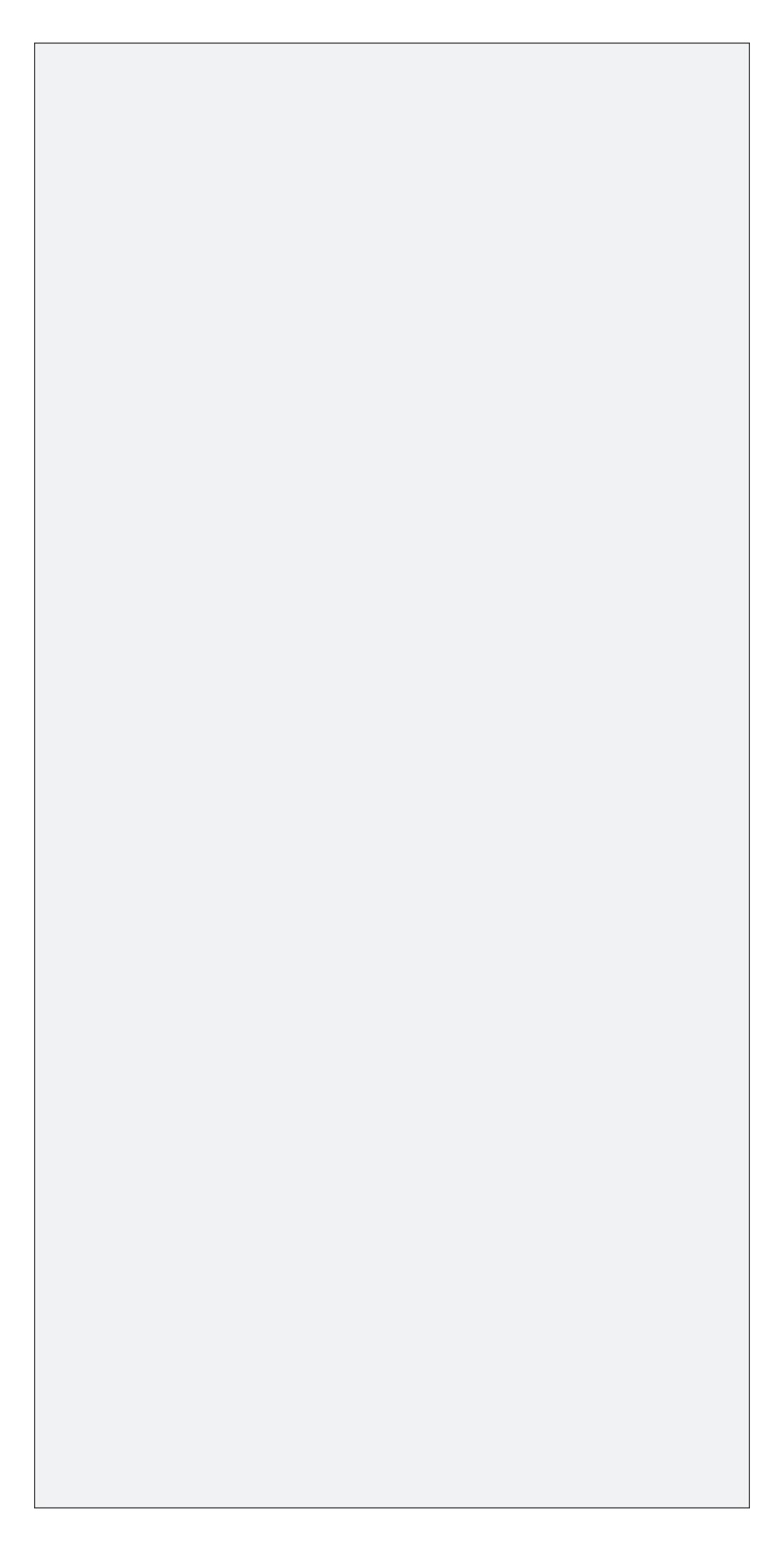
living with the health consequences of obesity. This includes not only children with pre-diabetes, but also those with sleep apnea, dyslipidemia (a disruption in the amount of fats in the blood), hypertension and females with polycystic ovarian syndrome (a hormonal disorder that can lead to infertility.)

A multidisciplinary team staffs the OAR clinic, including physicians, nurses, kinesiologists and dietitians. The program focuses on modifying behaviours, so that children and families can make positive changes with respect to their nutrition and physical activity. "The clinic works with families, not just the children. When a family works as a unit to make lifestyle changes, higher rates of success are seen," said Dr. Morrison.

#### One in four children in the study had pre-diabetes, putting them at serious risk of developing type 2 diabetes.

Research in adults has shown that making lifestyle changes to improve nutrition and exercise results in a reduced likelihood of developing diabetes. The OAR clinic is helping many of its clients make positive changes to their diet and physical activity.

In addition to helping these children and families in south central Ontario, the findings that will come out of this research will provide evidence to help other children and families around the world. Now that is food for thought.





"When we first began Keaton's journey at McMaster Children's Hospital, we had no idea what to expect or how to explain things to him. Then Maria came into our lives. She took Keaton under her wing and helped him understand everything that was going to happen to him. Maria was Keaton's comfort person in the hospital. She always made him feel like she had all the time in the world for him. Maria made Keaton feel special."

- Danielle Millar, Keaton's mom

Maria Restivo, Child Life Specialist, shown here with five-year-old Keaton Millar who was diagnosed in September 2007 with Rhabdomyosarcoma (cancer) and finished chemotherapy and radiation treatment in November 2008.

### Child Life Specialists: Champions for children in care

"Families that are hospitalized are in

the midst of incredible crisis, and to

be able to guide them and help them

cope through the process is very

a difference."

rewarding. You truly feel you make

- Maria Restivo, Child Life Specialist and

winner of the 2009 McMaster Children's

Hospital Family-Centred Care Award.

A hospital stay can be a very scary experience for anyone, especially children. The talent and expertise of a child life specialist can make the experience easier to endure for young patients and their families. Disruption to their normal routines, separation from their families and friends and anxiety about their treatment can be overwhelming.

MCH's long history of excellence in the child life field led to the development of an internationally recognized post-baccalaurate education and training program at McMaster University in 1989 – the only one of its kind in Canada.

The Child Life Program is an integral part of pediatric care at — Maria Rest McMaster Children's Hospital. Highly- winner of the trained child life specialists have — Hospital expertise in child development and related fields. They understand and support the emotional and developmental needs of children, while also effering emotional support to the family and

while also offering emotional support to the family and friends of young patients.

Child life specialists work with MCH patients to promote coping through play, education, and self-expression activities through the use of age-appropriate language, roleplaying and toys. With their help, children will understand what will happen to them before, during and after their procedure or treatment. When necessary, the specialists give support to medical staff such as providing a diversion during a procedure that may be uncomfortable. Child life specialists strive to normalize the hospital environment, foster continued growth and development, and act as advocates for

the needs of the child.

Another role of child life specialists is to regularly plan fun events, parties, and special guest appearances for the children. They help to make holidays extra special for patients who must spend them in hospital.

The following are some of the key programs that the Child Life Team supports: Bravery Bead Program for oncology patients; non-pharmacological approach to pain management; medical play that includes role playing with

equipment, medical dolls, and the Internet to prepare patients for procedures and treatments; Passport to Surgery Program where children have a passport that is stamped as they achieve certain steps through surgery (like getting into their pajamas, going into the operating room and waking up in the recovery room); and a special teen program focused on the specific needs and interests of teenagers, including computer activities, board games and discussion groups.



#### **Upopolis**

The McMaster Children's
Hospital Child Life Team
collaborated with TELUS and
Kids' Health Links Foundation
in the development of
Upopolis, the first, secure,
online social networking tool
for children in hospital care.

Upopolis.com provides the best features of social networking for young patients who often feel isolated when they're in the hospital. Upopolis offers a personal profile, secure mail, instant chat, discussion boards, personal blogs and links to child-friendly games. The site also features a homework site to help patients stay up-todate with their schoolwork, links to kid-friendly health and wellness information, and connections to other children in hospital.

The Child Life Team was integral in developing the child-friendly content of Upopolis. It describes in detail different diagnoses, treatments, tests, equipment and hospital staff so that children can be active participants in their own care and understand what is happening to them and why.



