



## No Defence Against Infection

The infections started shortly after she was born. Sarah from Stoney Creek suffered from frequent ear and chest infections. They kept returning even though she was regularly prescribed antibiotics.

“She got a really bad chest infection at the age of two,” says Sarah’s father, Mike. “She had trouble breathing, so we took her to McMaster Children’s Hospital. They determined that she had pneumonia and there was fluid in her lungs.”

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(Continued from page 1) A chest tube was immediately inserted to drain her lungs and she was admitted to the Pediatric Intensive Care Unit (PICU).

“A CT showed that she had holes in one lobe of her lung and it looked like Swiss cheese,” says Sarah’s mother, Carrie.

Emergency surgery was performed to repair the holes and drain the fluid.

Testing led to a diagnosis of primary immunodeficiency. This meant that Sarah’s body was unable to create antibodies to protect her from infections.

Almost immediately, she began receiving monthly injections to strengthen her immune system.

“Then she started to cough up blood one day,” says Mike. “We rushed

her back to the Hospital, where she needed immediate surgery because her lung was so damaged. They had to remove the lower lobe completely.”

After she recovered from surgery, Sarah began a new weekly regimen of immune-boosting injections.

“Her infections became far less frequent,” explains Carrie. “Nowadays, you can’t even tell that she has an immune-system deficiency. She’s a firecracker who dances competitively and enjoys playing sports.”

Sarah has regular follow-up appointments with various clinics, including respirology, immunology and dermatology.

“Sarah is alive today and thriving because of the teams at McMaster Children’s Hospital,” says Mike.



To watch a video about Sarah’s story or to donate, visit [hamiltonhealth.ca/sarah](http://hamiltonhealth.ca/sarah)

## A Change of Thinking about Eating Disorders

An eating disorder affects every aspect of a person’s well-being. Whether one is struggling with anorexia nervosa, bulimia or binge-eating, the potential health consequences are significant and dangerous.

“The Pediatric Eating Disorders Program at McMaster Children’s Hospital is one of the busiest in the province,”

explains Clinical Manager Paul Agar. “We take an evidence-based approach to care with our six-bed inpatient unit, four-bed day-treatment program and outpatient program. Both the inpatient and outpatient units have seen an ongoing increase in the number of patients who require care.”

Eating disorders are considered mental health disorders, so a patient’s way of thinking must be addressed.

“We use psychotherapy to provide patients with valuable new skills to deal with emotions,” says Dr. Jennifer Couturier, Medical Co-Director of the Pediatric Eating Disorders Program. “The therapy encourages patients to live in the moment and accept things they cannot change while also working toward goals that they can affect.”

Dr. Couturier works closely with many different specialists, including pediatricians, nurses, nurse practitioners, dietitians, psychologists and social workers to ensure that the entire family is receiving the support they need.

“It’s extremely rewarding to provide care for young patients and help them on their path to adulthood,” she says.



Clinical Manager Paul Agar with Medical Co-Directors Dr. Jennifer Couturier and Dr. Natasha Johnson

## Historic Endowment to Fund Cutting-Edge Research

Hamiltonians Margaret and Charles Juravinski are continuing their longstanding support of health care excellence with the creation of an endowment of more than \$100 million. This will be one of the largest legacy gifts in Canadian history, and it will provide up to \$5 million a year in perpetuity to the partnered organizations.

This endowment will result in the creation of the Juravinski Research Centre, a partnership between Hamilton Health Sciences, McMaster University and St. Joseph's Healthcare Hamilton. The Centre will conduct important medical research in such diverse areas as cancer, mental health, lung and respiratory care, and diseases of aging.

Hamilton Health Sciences Foundation is grateful to Margaret and Charles for leaving an incredible legacy that will inspire others to support outstanding health care for the region.



Margaret and Charles Juravinski

## Technology Talks

“We help patients communicate,” says Lindsay Bray, a clinical leader at Ron Joyce Children's Health Centre whose face lights up with pride when discussing the innovative work conducted at the Centre's Technology Access Clinic (TAC).

The TAC provides augmentative and alternative communication devices for patients who are unable to speak or write. The devices range from computers that patients control with their eyes, to text-to-speech programs on tablets.

“As patients develop, we find devices that suit their evolving needs,” says Susan Nall, Clinical Manager of Developmental Pediatrics and Rehabilitation. “We work with people who otherwise can't communicate and we support the discovery of their expressive vocabulary.”

The TAC serves pediatric and adult patients. The multidisciplinary team includes speech-language pathologists, occupational therapists who help patients with the physical aspects of accessing devices, biomedical technicians and communicative disorder assistants who program the devices.

“Many of our pediatric patients have developmental conditions like cerebral palsy or autism spectrum disorder,” explains Lindsay, “while our adult patients have degenerative conditions like multiple sclerosis, Lou Gehrig's disease or have suffered a stroke.”



Clinical Leader Lindsay Bray, Clinical Manager Susan Nall and Occupational Therapist Kimberly Carey Williams

One of the major goals in prescribing a communication device is to enhance a patient's quality of life.

“It's very rewarding to help our patients advocate for their wishes and to provide a sense of self-determination in such a comprehensive and innovative way,” says Susan.

## Special Spaces for Pediatric Cancer Care

The Pediatric Hematology/Oncology Clinic at McMaster Children's Hospital is a special place. It is a welcoming space where pediatric patients with any type of cancer receive treatment, including chemotherapy and blood transfusions.

An upcoming expansion is about to make the clinic even more special.

"Over the years, there's been a big increase in the number of kids we see," says Registered Nurse JoAnn



Registered Nurse JoAnn Duckworth

Duckworth, who has worked in the clinic for more than 20 years. "We're running out of space in our clinic to accommodate the growing number of patients."

With the support of donors, The Foundation is looking forward to funding this expansion. It will include the creation of distinct areas tailored to different age groups.

JoAnn is particularly excited about the new teen space. "This space will make it possible for teens to spend private time with other teens who are going through the same thing," she says. "It's important for teens to have an area where they can relate to each other on their own terms."

They will be able to spend time away from the noise and commotion of the main clinic space, where younger patients are playing and special programs are being run.

Another new area will be a quiet space where physicians and staff can consult with families and patients.

"We want this to be the most comfortable and fun place possible, even if we're giving chemotherapy," says JoAnn. "Teens can have privacy when they need it, but they can also spend time with the younger kids if that's what they want. The new clinic will be inclusive of everyone."

## Did You Know?

McMaster Children's Hospital Foundation is a proud member of Canada's Children's Hospital Foundations (CCHF), which raises funds and awareness for 13 children's hospitals across the country. It is the single largest non-government funder of children's health in Canada, and it is proud to run Children's Miracle Network's operations in Canada.

In 2018, CCHF received more than \$49 million from partners, programs

and donors. These contributions impact the highest priority needs at partner children's hospitals every day. This includes important medical research, education and prevention, critical needs, special programs and services, and vital equipment.

Thank you to CCHF for providing vital funding to enable the best possible patient care at McMaster Children's Hospital, including Ron Joyce Children's Health Centre.

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