

ENGAGING THE PATIENT

A LOCAL MOM'S EFFORTS TO RAISE AWARENESS ABOUT HER SON'S STRUGGLE WITH A RARE DISEASE IS PROVIDING NEW INSIGHTS INTO HOW MEDICAL RESEARCHERS CAN BETTER SERVE THE PUBLIC



BY JOEL SCHLESINGER
PHOTOGRAPHY BY MARIANNE HELM

Liz Crawford remembers the first weeks after her son Malachi was born as the most harrowing of her life.

Within hours of his birth, she knew something was awfully wrong. He wasn't able to feed like he should; he seemed weak. Malachi just didn't seem to be thriving like a newborn should.

The doctors deemed him too sick to go home, so Malachi, Crawford's second child, spent the first weeks of life in neonatal intensive care as doctors ran a battery of tests.

"I was absolutely beside myself," says Crawford, whose first child, Natasha, had been born healthy 12 years ago. "When the nurse is telling you to prepare for the worst, it turns your whole world upside down."

➔ Team Malachi: A group of clinicians, researchers and families affected by Hirschsprung's Disease are working together to help improve the lives of families and patients like Malachi Hofer (centre front) living with the condition. They include Dr. Melanie Morris, Dr. Nathan Wiseman, Liz Crawford, Kristy Wittmeier, Cindy Holland and Kendall Hobbs-Murison.

After a month of camping out at Children's Hospital, Crawford learned that her son was diagnosed with a rare gastrointestinal disorder called Hirschsprung's Disease (HD), a condition that impedes the colon's ability to function.

"The disease makes it impossible for him to (defecate) without help," says Crawford. "He couldn't have bowel movements, and that obviously affected his whole system."

The diagnosis that day in 2008, however, was only the beginning. The first two years were equally



Dr. Richard Keijzer is a surgeon at Health Sciences Centre Winnipeg and a member of the research team.

challenging as Malachi was hospitalized more than 20 times.

"I was very frustrated," she says. "There was really no information out there on how to care for a child with Hirschsprung's."

Yet rather than despairing, Crawford took action. In 2011, she decided to develop a social media campaign to provide a forum for families to exchange information about Hirschsprung's and to raise awareness about the condition.

Entitled "Shit Happens," the name of the campaign raised some eyebrows. But Crawford, a former model and the owner of Swish Productions, says that from a marketing perspective, it only made sense.

"Many children with HD suffer from chronic constipation and occasional bowel obstruction," she says. "For a child and family with HD, the idea of 'shit' happening tends to bring feelings of joy and relief. When a bowel movement finally occurs, it is not for the faint of heart... hence the name. Laugh or cry? May as well laugh."

To help launch the effort, Crawford went to her good friend Mike Silver at Silver Jeans who produced several thousand T-shirts with the Shit Happens

campaign did more than raise awareness about a rare disease. It also triggered a chain of events that helped launch a major research project designed to examine how patients could have more say in medical research.

That's because the online campaign caught the eye of the local medical community, including Malachi's pediatric surgeon, Dr. Nathan Wiseman, and one of his colleagues, Dr. Richard Keijzer.

They quickly realized that her worldwide network of Hirschsprung's families represented a unique opportunity to interact with a large group of patients that would be impossible to find in Manitoba alone.

As a result, the surgeons approached staff at the George and Fay Yee Centre for Healthcare Innovation (CHI) to see if they would be interested in investigating whether Crawford's social media campaign could help direct better care – and more research – for children with Hirschsprung's Disease.

Funded in part through a \$6.25 million grant from Research Manitoba, CHI is the province's hub for research support, providing health-care investigators with the tools to develop more meaningful, innovative and effective research. The

"We want patients and family members to be partners in the research process."

logo. The campaign – which includes Twitter, a blog and a Facebook page called Hirschsprung's Community – was extremely successful. Not only were friends and family wearing the shirts, celebrities and even Victoria's Secret models were donning them as well.

Soon, hundreds of parents from around the world were using the Hirschsprung's forums to exchange their knowledge about the illness. "It went viral," she says.

But Crawford's

CHI team was intrigued by the doctors' request, none more so than Kristy Wittmeier.

As CHI's Director of Knowledge Translation, Wittmeier's role is to help ensure important research is used to improve health outcomes.

With a background in physiotherapy, Wittmeier says her work as a clinician has helped prepare her for her role at CHI. She also has a strong interest in the involvement of patients in health research, with the goal of making research more responsive to the needs of patients. "My clinical training and experience has clearly highlighted the importance of listening to patients as the experts of their unique situation," she says. "So, it was very easy to make the connection between involving patients in their clinical care and involving patients

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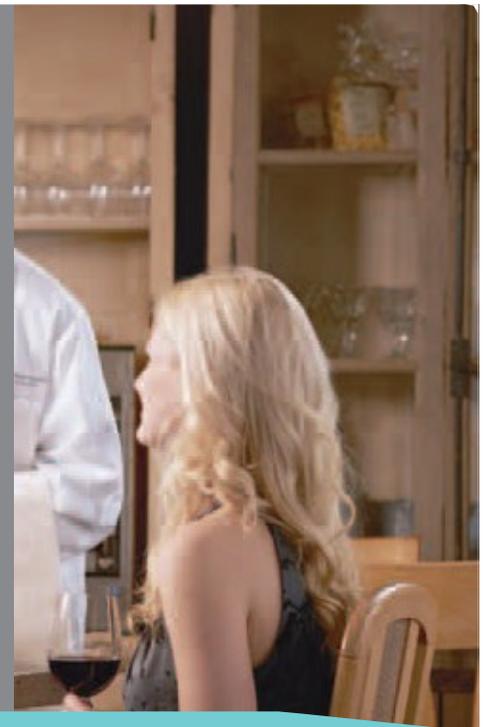
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New agency to support research and innovation

Research Manitoba was created earlier this year after the provincial government consolidated funding for research in health, natural sciences, social sciences, engineering and the humanities.

In doing so, the province merged the funding operations of the Manitoba Health Research Council, the Manitoba Research and Innovation Fund, the Health Research Initiative, and the Manitoba Centres of Excellence Fund.

The new agency's mandate is to promote, support and co-ordinate the funding of research in Manitoba. Research Manitoba is chaired by a 17-member board, headed by Dr. Brian Postl, Dean of the Faculty of Health Sciences at the University of Manitoba, and reports to the Minister of Jobs and the Economy.



in research that could have an impact on their care.”

That interest grew when Wittmeier attended the Standards for Research in Child Health Summit held in Winnipeg in 2012. The keynote address was delivered by Elizabeth Vroom, founder and President of Duchenne Parent Project Netherlands and the global community, United Parent Projects Muscular Dystrophy. Muscular Dystrophy (MD) is a rare genetic disease that progressively robs children of their strength and mobility as they age.

In her talk “Clinical Research to Advance Knowledge: A Parental Perspective,” Vroom spoke passionately about the importance of having the patient voice heard in research. She discussed the disconnect that can exist between research and what those living with the disease need. For example, there was a large body of research looking at how to improve leg strength and walking in younger boys with MD, but very little research that focused on those who were wheelchair bound and looking for ways to improve their fine motor control or leverage technology to maximize their ability to meaningfully participate in daily activities, says Wittmeier.

“Her message has stayed with me,” she says. “It was very clear that we have to ask individuals who live with a condition what is important to them when we start a research project. That input will help focus the research question to ensure the

project has maximum impact on the lives of patients.”

Wittmeier says she immediately saw parallels between Crawford's initiative and Vroom's. “Both of these initiatives are bringing families together to support each other and to help improve the care their children receive.”

The fit between Crawford's campaign for Hirschsprung's Disease, and the work of the Knowledge Translation platform at CHI was also easy to see. “The campaign spoke to our priority of involving patients and members of the public in research,” she says. “The opportunity to partner with Liz and her community of caregivers in a research project to improve resources for families was very exciting.”

In short order, Wittmeier, along with a dedicated research team, developed a research proposal which attracted funding from the Manitoba Institute of Child Health and the University of Manitoba.

Wittmeier and fellow lead researcher Dr. Richard Keijzer also invited Crawford to become a co-investigator in the study and contribute to the project – an unusual step given that studies are usually conducted by academics. However, growing evidence shows that engaging patients earlier in the research project, especially as project team members, is associated with more relevant research.

“We want patients and family members to be partners in the research process to help inform the research priorities, question, study design and output.”

The project had two goals. The first objective was to examine the effectiveness of Crawford's social media efforts to build a community to raise awareness about Hirschsprung's. The second is part of a larger priority within the Knowledge Translation platform, to determine how to best make involvement in research more accessible to patients and the public.

The first phase of the study involving an examination of the social media campaign has concluded, and the results are to be published in an upcoming edition of *The Journal of Medical Internet Research*, a leading medical informatics publication.

(To read the article, visit www.jmir.org and search for: *Analysis of a parent initiated social media campaign for Hirschsprung's Disease*, Wittmeier K, Holland C, Hobbs-Murison K, Crawford E, Beauchamp C, Milne B, Morris M, Keijzer R, *J Med Internet Res* doi:10.2196/jmir.3200.)

It confirmed the potential power of social media to engage parents of children with rare diseases to develop better treatment. “The initial part of the study worked within the community that Liz had created to identify priority concerns of members,” Wittmeier says.

As noted in the study, the success of the social media effort was due in part to a good marketing campaign. After all, starting a Facebook page dedicated to helping families with Hirschsprung's Disease is not much help if those families do not even know it exists.

As the study explains, the campaign name was purposefully chosen to create a brand that would stand out. “The campaign name was chosen to resonate with potential community members and break the barriers of an otherwise socially awkward topic,” according to the study.

And the proof was in the research. According to the study, the blog (<https://roosjourney.wordpress.com/>) was visited by 387 people on the first day alone. Since then, there have been more than 5,400 views of the blog from readers in 37 countries.

The Facebook page also proved to be popular. The report says the page attracted 1,130 monthly users, with the average post reaching about 295 people during a 28-day period. A responsiveness assessment of the page revealed that one question received as many as 143 views and 20 responses within hours of being posted.

The study also revealed that many families dealing with Hirschsprung’s had common concerns, most often relating to the provision of ongoing care for children who may face challenges for at least the first decade, if not longer, of their lives.

Toilet training was at the top of the list. Because children with Hirschsprung’s Disease cannot sense a need to defecate, this developmental milestone involves different teaching techniques than used for children who do not have the disease. Families also require support regarding post-operative care, including how to recognize complications like infection.

The study also underscored the difficulties of providing treatment and care for people with rare diseases.

Naturally, most health-care resources are devoted to more common conditions: heart disease, cancer and diabetes, for example. Less common conditions receive fewer resources for care and research. With fewer patients to engage, researchers and other stakeholders struggle to design initiatives that are responsive to patients’ needs. This has far-reaching negative implications.

Malachi’s experiences illustrate the point. While some of his hospitalizations were unavoidable, others might have been prevented if better treatment protocols would have been easier for caregivers to access.

For Crawford, ongoing primary care for her son in the first few years often fell on the surgeons who performed procedures to treat his condition. “The surgeons are fantastic, but they’re not always the ones that can deal with ongoing care,” she says. “It’s not like they’re meant to be primary health-care providers, so these kids can fall through the cracks a little bit.”

As the study shows, using social media to create larger communities not only allows for sharing of information, it also creates opportunities for more focused research to help identify and address where there are gaps in knowledge.

“Having this global community, you can work with a much larger population to help identify what the priority questions and concerns are,” says Wittmeier. “You can’t achieve that large of a sample for a rare disease if you’re just working with Manitoba patients.”

As one might expect, Crawford’s campaign and family network has drawn interest from other researchers and clinicians, including Dr. Allan Goldstein, an associate professor of Surgery at Harvard Medical School and a pediatric surgeon at Massachusetts General Hospital. Simply put, the study has

“Involving patients or their family members in developing a research project makes the research better.”

created an opportunity for families dealing with Hirschsprung’s to communicate to researchers what matters most to them, which, in turn, can help improve both research and treatment protocols. “It’s not only addressing what patients want to know, but it helps answer how we get that information back to them,” Wittmeier says.

In addition to surveying information provided by families dealing with Hirschsprung’s, Wittmeier and her team also surveyed pediatric surgeons across Canada to get a sense of their experiences with the disease and what they would like to know from future research. The research team hopes that surveying both health-care providers and parents of children with the disease will lead to the development of better studies and better treatment.

As the study notes, “The (social media) sites are presently filled with questions from families who continue to struggle to manage even after surgical intervention for (Hirschsprung’s), presenting health-care professionals and researchers with the opportunity to provide families with evidence-based information to guide care.

Families rely on these forums for support from other caregivers, but clinicians and researchers are not represented within these social media communities. Partnerships between communities of caregivers, health clinicians and researchers mediated through social media could provide unprecedented opportunity for consumer-driven research.”

Adds Wittmeier: “There are excellent examples of patient engagement in health and research within our health region, community organizations and in specific research disciplines. However, patient engagement in research is not yet standard practice. With studies like this, and the work within the Knowledge Translation platform, we want to build on existing successes and explore new and innovative ways to ensure the patient voice is consistently heard and authentically represented in health research.”

Going forward, the Knowledge Translation platform is working to build the systems and processes to more broadly support the continued involvement of patients and the public in research. “Involving patients or their family members in developing a research project makes the research better.”

For patients and caregivers like Crawford, working with Wittmeier has already paid dividends.

For one thing, it has vindicated her efforts and confirmed what she has always known – that the patient’s opinion is valued. But more importantly, the research will hopefully soon lead to better treatment and access to more information so families with children with Hirschsprung’s Disease will not have to go through the same painful trial and error she and her son sometimes endured.

Today, her son is six years old and starting school. He is healthy, for the most part, but he still faces many challenges. Crawford says better-informed research along with standardized care guidelines will certainly make life easier.

Perhaps even more significantly, she says, families dealing with the disease know they are no longer on their own. They have a community of families, health-care providers and researchers walking alongside on their journey.

“Now everybody is involved in trying to make it better, which is all great,” she says. “And it will be even better once we can finally use all of this information so experts can come together to address the concerns and needs of parents caring for children with this disease.”

Joel Schlesinger is a Winnipeg writer.

Knowledge in motion

Winnipeg centre aims to improve health care

The George and Fay Yee Centre for Healthcare Innovation (CHI) is dedicated to ensuring the latest medical research is used to improve patient care in Manitoba.

The centre was launched in 2008 with a \$2.5 million grant from Dr. George Yee, a graduate of the University of Manitoba's Faculty of Medicine, and his wife, Fay. Sadly, Dr. Yee passed away on Nov. 11, 2014, and even in his last days the celebrated pathologist and philanthropist continued to give back.

Since its inception, CHI has continued to expand through collaborations with Research Manitoba, the Province of Manitoba, and the Canadian Institutes of Health Research (CIHR).

As a partnership between the Winnipeg Health Region and the University of Manitoba, CHI supports the development and application of health research and innovation through the following platforms: Knowledge Synthesis, Knowledge Translation, Health Systems Performance, Evaluation, Data Science, Project Management and Clinical Trials.

"Essentially, we work with the health sciences community to advance the science of health-care research and apply these learnings to improve patient experiences and outcomes," says Frank Krupka, Executive Director of CHI. "We do this by providing a variety of services throughout our seven platforms including consultation, project support, methodological expertise and training and career development."

CHI's vision is aligned with the

Canadian Institutes of Health Research (CIHR) strategy for patient-oriented research. As the federal agency that provides most of the funding for health research across the country, CIHR has a large say in the nature of medical research taking place in Canada. Its primary aim is to support research that will improve health care in a number of broad areas.

CHI's Knowledge Translation platform plays an important role in doing just that. Headed by Kristy Wittmeier, it helps move research that will improve health outcomes into practice. In addition to efforts related to patient engagement in research, the platform assists stakeholders with the development and implementation of knowledge translation plans.

Helping researchers incorporate knowledge translation into their overall plans when applying for grants is something that is becoming increasingly important, says Dr. Terry Klassen, Academic Director of CHI. Simply put, a study is unlikely to receive funding without explaining how its findings may improve health care.

"Knowledge translation is incredibly important because we do all this research that's supposed to improve the lives of people, but unless those findings get used, it doesn't benefit people," says Klassen, an

internationally-renowned researcher who is also CEO and Scientific Director of the Manitoba Institute of Child Health.

While it seems like common sense, important new medical knowledge derived from the latest research isn't always put into practice. "We know there's been a huge gap," says Klassen. In fact, it's not just a concern for new research. It's a challenge to ensure that best practices – evidence-based knowledge that has been around for some time – are applied as well, he adds.

One of the obstacles with translating new and existing knowledge into practice is that health-care systems



are incredibly complex, involving many stakeholders, all with different objectives and concerns. Implementing new initiatives takes time, co-operation and co-ordination. That's why the role of CHI, particularly the Knowledge Translation platform, is so important. Currently, the platform has several initiatives and research projects underway to investigate how the latest medical knowledge can be used to improve the health outcomes of Manitobans. They are:

Shit Happens: This groundbreaking project is spearheaded by Wittmeier, and involves investigating how social media can be leveraged to help develop better research and treatment protocols for families taking care of children with Hirschsprung's Disease, a rare gastrointestinal condition. More broadly, the research aims to illustrate the importance of patient engagement in medical research and developing care guidelines for caregivers and practitioners.

EvidenceNetwork.ca: Founded by Dr. Noralou Roos, one of the province's top health policy researchers, the Evidence Network of Canadian Health

Policy, commonly known as EvidenceNetwork.ca, is an evolving Canadian health-care resource designed with the needs of journalists in mind. The project links journalists with health experts to provide access to credible, evidence-based information. "Evidence Network creates original articles, infographics, posters and videos on health policy topics for publication in the mainstream media," says Carolyn Shimmin, a knowledge translation co-ordinator at the CHI. Since its inception in 2011, EvidenceNetwork.ca has had more than 1,500 articles published in mainstream media.

TREKK: Short for Translating Emergency Knowledge for Kids, this knowledge mobilization initiative involves a network of researchers, health-care providers, national organizations and health consumers who share the same goal: improving emergency care for children. Across most health-care settings in Canada, the majority of children requiring emergency care are treated in general hospital emergency departments. As a result, the latest medical information regarding pediatric care may not always be

available, particularly in smaller health centres. TREKK aims to create a national network that provides a trusted source for easy access to best practices in pediatric emergency care. Carly Leggett, the knowledge translation co-ordinator helping guide the project, is working with partners across 12 pediatric research/teaching hospitals and 37 general emergency departments in Canada, including the Health Sciences Centre Winnipeg's Children's Hospital, Seven Oaks General Hospital, Bethesda Regional Health Centre in Steinbach and Portage District Hospital in Portage la Prairie.

Choosing Wisely Canada:

CHI is partnering with Diagnostic Services Manitoba on a number of Choosing Wisely projects. Choosing Wisely Canada is a campaign to help physicians and patients engage in conversations about unnecessary tests, treatments and procedures, and to help physicians and patients make smart and effective choices to ensure high-quality care. Laurie Ringaert, the knowledge translation co-ordinator for the project, works closely with a variety of stakeholders on this project.



Centre for Healthcare Innovation team members, from left: Patrick Faucher, Carly Leggett, Frank Krupka, Caroline Shimmin, Dr. Terry Klassen, Laurie Ringert, Kathryn Sibley.