

Sharing Success



CYHRNet: Creating Connections and Sharing Success

Welcome to the Summer 2009 issue of the CYHRNet newsletter *Sharing Success*.

The research teams you will see featured in this newsletter have bloomed with CYHRNet support. They are conducting innovative, interdisciplinary research that will posi-

tively impact child and youth health practice and policies.

We are proud of what our members are doing and we are proud of our role in their achievements. Indeed, CYHRNet is very proud to be sharing success.

Researcher receives \$8.1 million to launch centre for understanding and preventing infection in children

CYHRNet an early supporter of Dr. Speert's research centre vision

When Dr. David Speert first envisioned the Centre for Understanding and Preventing Infection in Children (CUPIC), he had one very simple – but very lofty – goal: understand why children get sick and then prevent it from happening.

"It sounds like a pretty simplistic concept," admitted Dr. Speert, "but it hasn't been tackled effectively by a consolidated group."

That's a gap Dr. Speert is working to fill. In late 2006, he was awarded a Canada Foundation for Innovation (CFI) Grant. The funding, which totals \$8.1 million with matching funds from the province and the BC Children's Hospital, will finally make Dr. Speert's CUPIC dreams a reality.

It has been a long road for Dr. Speert, who has been nurturing the CUPIC concept since he became division head of infectious and immunological diseases at UBC's Department of Pediatrics.

The division was established in 1991 with Dr. Speert and Dr. David Scheifele as its founding members. The pair's working relationship, however, stretched back to the 1980s.

Nonetheless, Dr. Speert soon noticed their research collaborations beginning to taper off. As Dr. Scheifele developed an interest in immunization program evaluation, conducting research primarily in a dry lab setting, Dr. Speert was on the opposite end of UBC's Oak Street campus, conducting wet lab research on the molecular epidemiology of infections.

Although the two research approaches complemented each other and the researchers continued to look for ways to collaborate, logistics made it difficult.

"There was a lot of expertise on the campus in the area of infection but it was spread out over several buildings," explained Dr. Speert. "The idea sprang out of a need for better adjacency and better facilities in which to facilitate collaboration."

Although still in its infancy at the time, CYHRNet recognized the potential of Dr. Speert's idea to build research capacity in this important area of child and youth health.

In 2005, the network awarded Dr. Speert a seed grant. The funding enabled him to build support for his vision by presenting it to other child and youth health researchers at CYHR-



CUPIC facilities will occupy the fifth and fourth floors of the new Translational Research Building, pictured here. The building is located at the BC Children's Hospital in Vancouver, BC.

Net's Inaugural Workshop. He found researchers embraced the idea.

"There was a lot of enthusiasm around the room," he said. "There was nothing like this anywhere in the world, as far as we knew."

Despite the support of his fellow researchers, Dr. Speert struggled to make CUPIC a reality. He submitted three applications to CFI before receiving funding – learning from each rejection how to better tailor his application to CFI's multidisciplinary review committee.

Finally, in November 2006, Dr. Speert was awarded CFI funding. Construction began on the centre's facilities, located in the Child and Family Research Institute's Translational Research Building. The building is designed to facilitate collaboration by housing adjacent wet and dry labs and a clinical trials unit.

A particular source of pride for CUPIC will be its Class 3 containment unit. The \$3 million unit will allow researchers to work with highly virulent bacteria like TB in a safe environment.

Construction is now nearing completion for CUPIC. Researchers are expected to move into the state-of-the-art facility in early fall.

CYHRNet is now collaborating with Dr. Speert and the CUPIC team to create a website for the centre. The site will be a hub for researchers interested in the prevention of childhood infection, providing the latest research news and materials.

Our Mandate | To promote and facilitate research on key transitions in the development of children and youth

Our Mission | To improve the health and well-being of all children and youth

Our Vision | The BC Child and Youth Health Research Network is a vibrant collaborative research community that creates and sustains responsive relationships among researchers, decision-makers, service providers and children, youth and their families. We foster excellence in multi-disciplinary health research, training and knowledge exchange to improve the health and well-being of all children and youth.

CUPIC in Cape Town



Dr. Speert, left, and the CUPIC team are already hard at work, collaborating with researchers in Cape Town, South Africa.

The city's high rates of TB and HIV infection make it an excellent research ground to study why children get sick and how infection can be prevented.

With CUPIC's resources and expertise, they plan to establish a birth cohort study in which 30,000 infants will be followed for 20 years. The study will evaluate the reasons for TB vaccine failure, investigate the impact of AIDS on innate immune defense and investigate the role of innate genetic elements in the defense against TB.

"It's a long and ambitious study," Dr. Speert said, but it will give researchers access to a rich dataset with information on genetics and nutrition as well as psychosocial and environmental assessments.

"We're creating a platform on which many questions can be asked."

CYHRNet supports essential end-user involvement in injury prevention research

From ages one to 19, injury is the leading cause of death for Canadians. It kills an average of 390 children, aged 14 and under, and hospitalizes another 25,500 each year.

Indeed, of all childhood conditions, injury accounts for the greatest number of days of hospital care.

Yet, says CYHRNet Co-Leader Dr. Ian Pike, injury prevention has struggled to find a place in academia.

"I don't think you'd ever find a degree in any applied health or kinesiology program with injury prevention as a major," he said.

CYHRNet and Dr. Pike are working to change that. By making injury prevention a network priority initiative, CYHRNet is building research capacity in this important area of child and youth health.

Key to the process is involving end-users in injury prevention research.

"These end-users bring practical knowledge and experience," said Dr. Pike.

"They're in the field dealing with the delivery of injury prevention programs and see first-hand what works and what doesn't."

It is this important input that end-users brought to Dr. Pike's recent CIHR Strategic Teams in Applied Injury Research grant application. The application included 18 end-user partners such as the Canadian Red Cross, the BC Ministry of Healthy Living and Sport and the Assembly of First Nations.

However, this type of collaboration is not new for Dr. Pike's team.

In 2007, CYHRNet support enabled the team to consult with policymakers and practitioners nationwide, culminating in the development of 34 injury indicators designed to help researchers compare injuries between groups and places over time and better inform practice and policy.

The work also inspired a parallel project contracted by Health Canada's First Nations and Inuit Health Branch to develop injury indicators for First Nations and Inuit children and youth.

The team then moved on to injury prevention policy indicators. Responding to input from end-users like the Child Welfare League of Canada and the Public Health Agency of Canada, the team focused on child restraint, graduated licensing and bicycle helmet regulations, compliance with CSA playground standards and the presence of co-ordinated pediatric trauma services.

CYHRNet support allowed them to put forward a successful research proposal for a \$75,000 CIHR Operating Grant.

While this marked a significant step forward in Canadian injury prevention research, Dr. Pike and his team remained forward-looking.

"Being able to plan injury prevention initiatives is really dependent on an understanding of the current state of affairs," said Dr. Pike.

In that light, CYHRNet funded a February 2008 *Injury Indicators Forum* in Vancouver



"CYHRNet has been the angel investor in our injury indicators teams," said Dr. Pike. From supporting end-user meetings to designing and laying out research reports, "they have been able to provide the perfect resource at the perfect time."

which brought together a national team of researchers, policymakers and injury prevention practitioners to assess the 'state of the nation' for child and youth injury research. This resulted in a Letter of Intent for a CIHR STAIR grant.

When the team was invited to submit a full application, CYHRNet sponsored two additional meetings in 2008, enriching the team's STAIR grant proposal by further engaging end-users and researchers in a process of true knowledge translation. End-users learned more about the relevance of the injury indicators, while researchers learned more about end-users' research needs.

"We're very fortunate, in that it's not a stretch to involve the end-users," Dr. Pike said. "They've been there from the get-go. It's been the end-user population that's driven the agenda and driven the progress in some cases."

End-User Feedback

	<p>"Your team has demonstrated your determination to meaningfully involve end-users in this research ... There is no question of the relevance and significant importance of your proposed research at the national and international level."</p>
	<p>"[Dr. Pike and his team] have a history of leadership in research, are well-connected to the ... community, have a reputation for excellent team management, strong knowledge translation skills, and a history of working with partners to disseminate information widely among different sectors."</p>
	<p>"I have great belief that the result of your pivotal work will be a catalyst to strategically drive forward injury prevention for children and youth in BC and across Canada."</p>
	<p>"ThinkFirst Canada believes research, like yours, that examines behavioural, social and cultural risk factors as they relate to unintentional injury is of tremendous value to our work. We believe people in all sectors of a community can engage in understanding risk and how risk can be managed."</p>

Key STAIR Grant Initiatives:

The STAIR grant application was submitted in April 2009. If successful, it will provide support to the team for up to five years in some of the key initiative listed below:

- Produce a highly-interactive web-based 'dashboard' that injury prevention practitioners, policymakers and researchers can use to understand the current state of child and youth injury prevention in Canada.
- Provide an online forum for policymakers, researchers and practitioners to communicate and share reports, materials and links to relevant injury prevention information.
- Develop a training program in injury prevention, providing grants to recruit masters, PhD and post-doctoral students to join the research team. Training opportunities will also be available for end-user partners.

Support research on:

- The burden of injury for severely-injured children and their families: what are the requirements for rehabilitation, recovery and reintegration into normal life and activities?
- Canada's pediatric trauma systems: are they providing the right care at the right time in the right place?
- High-risk populations: are some kids more risky than others? If so, what characteristics make them more risky?
- The supervision of young children: what type of supervision results in reduced injuries and safer home environments?
- High-risk behavior: specifically, youth behavior in snowboarding terrain parks and other sports injuries.
- Pedestrian safety in virtual reality labs. With geospatial information, researchers can accurately recreate real locales in a virtual reality lab; they can then put children in the location, observe their behaviour and determine how to improve the situation.

CIHR awards \$274K to team of researchers, nurses for infant night-waking study

Successful grant application would have been 'impossible' without CYHRNet support: Dr. Wendy Hall

Dr. Wendy Hall knows a lot about the impact of infant night-waking.

She's a sleep consultant for the Vancouver Coastal Health Community group. She's a Canadian Sleep Society infant sleep specialist. She's even been described as an 'infant sleep guru' on the Vancouver-based website www.fussybaby.ca where she teaches new parents how to ensure a good night's rest for their babies.

However, this 'infant sleep guru' is also a full-time professor and PhD program co-ordinator at the UBC School of Nursing. This means that when she attempts to help families with infant sleep problems, she's largely working off the side of her desk.

It's a problem she shares with public health nurses across the province. Despite a general consensus that most pediatric sleep problems are behaviourally based, there is no standard intervention for infant night-waking. When nurses try to help families with infant sleep issues, they are going above and beyond an already overwhelming amount of regular daily duties.

In 2008, CYHRNet recognized this problematic omission in health-care services for new parents and awarded a seed grant to help Dr. Hall close the gap. With this support, Dr. Hall and her team were able to successfully apply for \$274,387 from the CIHR Randomized Controlled Trials Program.

The *Rocky Sleep Study* will help determine whether parents who receive group teaching about infant sleep, coupled with follow-up phone calls from public health nurses, will reduce their infants' night-waking and their perceptions of their child's sleep difficulties.

However, it is the study's diverse team of 13 co-investigators that truly makes it unique. The team includes researchers from UBC's Departments of Pediatrics and Statistics and McMaster University's Departments of Obstetrics and Gynecology and Clinical Epidemiology; it also includes five public health nurses, one clinical nurse specialist and the assistant director from the Vancouver Coastal Health Authority.



"I couldn't have done this without the seed grant," said Dr. Hall of her successful CIHR funding application. "It would be impossible."

This collaboration between end-users and researchers couldn't have happened without CYHRNet's support, Dr. Hall said. A large portion of the seed grant funding went to hiring a graduate student to support the grant development activities. This included assisting the public health nurses prepare CVs for submission – a process most had never gone through before.

Despite the added challenges, Dr. Hall said it was imperative to have the nurses listed as project co-investigators.

"I wanted there to be recognition that they were making a significant intellectual contribution to this project," she said. "That they weren't just collaborators who were allowing this to happen."

Indeed, it was in part the public health nurses' enthusiasm that helped spur the project along.

In 2003, Dr. Hall completed a small pilot study which evaluated an intervention aimed at resolving behavioural sleep problems in six- to 12-month old infants. The results were encouraging in the test group of 35 infants.

"We'd showed that we made a difference in this small pilot group," said Dr. Hall.

When she presented these findings to public health nurses they were eager to give the intervention a try. Moreover, they were eager to become involved in a larger study of the sleep intervention that – if successful – could lead to a standardized sleep intervention for health-care service providers across BC and beyond.

The study aims to enroll 240 infants beginning in September 2009 and is expected to be completed in December 2012.

But for Dr. Hall and her team, that is only the first step. They hope the study will lead to the implementation of a standardized sleep intervention in BC health centres – a prospect which is already showing promise.

At CYHRNet's 2008 AGM, Dr. Hall presented a poster on the proposed study. Through this, she connected with clinicians from other health authorities who were eager to implement the intervention in their jurisdictions. These connections will be an important step toward standardizing the intervention.

Dr. Hall said she also hopes the study increases recognition of public health nurses' important role in assisting new parents with infant sleep issues.

"It's integral to the practice that public health nurses do, but don't get recognition for," said Dr. Hall. "I want there to be a critical mass out there to support this."

The Infant Sleep Issue:

By Dr. Hall's estimates, she has helped over 700 families in BC, Ontario, Quebec, Alberta and the United States deal with infant sleep issues.

"What this indicates," Dr. Hall said, "is that there's a very large problem with infant sleep out there."

Indeed, behavioural sleep problems affect up to 50 per cent of infants.

Frequent night-waking in infants is associated with parental stress and fatigue, family tension and maternal depression. Moreover, infants who experience interrupted and fragmented sleep trajectories which carry on into their second and third year experience decreased cortisol levels and are associated with hyperactivity, inattention and lowered ability at cognitive tasks.

These children, Dr. Hall says, are often identified in daycare as 'problem kids' – a label that can follow them into the school system and through their lives.

CYHRNet and CIHR focus on chronic care management for children, youth

The prevalence of chronic diseases is increasing in high-income countries like Canada, creating a severe impact on health-care systems.

Yet, says CYHRNet Co-Leader Dr. Jean-Paul Collet, chronic disease management strategies focus almost exclusively on adults. In recognition of this, CYHRNet has made chronic health issues one of its priority initiatives. The network is committed to building research capacity in this important child health area, and a planned workshop will take the first crucial steps.

In 2008, CYHRNet provided support to Dr. Collet for a successful CIHR Partnerships for Health Systems Improvement Grant. The

PHSI program aims to support teams of researchers and decision-makers interested in conducting applied and policy-relevant health research.

This CIHR grant will fund the workshop *Optimal Management of Infants, Children and Youth with Chronic Conditions*, which will bring together clinicians, families, public health decision-makers and researchers to develop models of care for children and youth with chronic conditions and identify realistic ways to implement these models in BC, considering health priorities, geographic context, cultural values and other specific constraints.

It's an important topic, says Dr. Collet,

because most chronic diseases in children and youth span across several important lifestyle stages, including the transition to adulthood, and may affect the child's development, social integration and school performance with possible lifelong consequences.

"Because of the unique features of chronic conditions in infants, children and youth," said Dr. Collet, "it is necessary to develop, implement and evaluate optimal models of chronic pediatric care that go beyond the simple translation of adult chronic care models."

The workshop is expected to lead to a March 2010 CIHR grant application.

CYHRNet helps launch TRU community-based youth health research centre

Centre enables community organizations, youth to influence research directions in the Interior

Growing up in a rural community, youth can often feel misrepresented and misunderstood by urban outsiders.

To ensure this isn't the case when it comes to youth health research, CYHRNet has helped Thompson Rivers University researcher Natalie Clark create the Centre for Community-Based Youth Health Research.

The centre aims to raise the profile of rural youth by enabling them and their service providers to be co-leaders in developing the agenda for research and community health planning. It's an important step toward attaining CYHRNet's vision of creating and sustaining responsive relationships between researchers, service providers and youth.

Ms. Clark grew up in the Interior but spent many years practicing in Vancouver after completing her masters in social work at UBC.

When Ms. Clark returned to the Interior 17 years after leaving the region, she began to see the rural community through a different lens. She realized that as the geography changed so did the issues faced by the youth living within it.

Moreover, she realized these unique issues were not always accurately reflected in the current body of youth health research.

"I really got a sense that there wasn't any research being done in Kamloops that was community-based or even locally-based," Ms. Clark said.

It's a gap CYHRNet recognized as well; the network provided funding to Ms. Clark



Centre for Community-Based Youth Health Research

"It was fundamental," said centre coordinator Natalie Clark of CYHRNet's support. "Without that we wouldn't have had the first roundtables that got people excited and started the momentum."

for an October 2007 *Transitioning into Adulthood Roundtable* in Kamloops. The event brought together over 65 attendees from rural communities. Participants included marginalized youth, youth with varying ethnic and class backgrounds, youth who were gay, bisexual and two-spirited and disabled youth. Other attendees included representatives from TRU, UBC Okanagan, the City of Kamloops, community non-profit agencies, government ministries and Interior Health.

"There was a huge turnout," Ms. Clark recalled. "And what came from that was a strong interest in doing community-based research."

The youth requested that they have a voice in the community about issues that impact their lives, rather than having decisions made for them without their input.

From this, the Centre for Community-Based Youth Health Research was born. The centre has grown considerably in its short life and now boasts more than 10 community partners, including the City of

Kamloops, the Boys and Girls Club of Kamloops, Interior Health and the Kamloops Immigration Centre.

These community partners are setting the centre's research agenda: they propose research questions, and the centre works to support them by providing necessary resources.

An example is a public health nurse who is working in partnership with Ms. Clark on a research proposal around the impact of gender, age and geographic location in accessing the emergency contraceptive Plan B.

All stages of the research project are tied back to the community, from the development of the proposal to the dissemination of findings.

"It works really well with youth," Ms. Clark said of the process. "It engages them and allows them to influence the research agenda."

The centre is eagerly planning its next steps, examining strategies to positively influence community health planning by distributing fact sheets to key government decision-makers, presenting research findings to local schools and exploring avenues for youth to write about their research in a youth-friendly avenue. All activities are aimed toward achieving the centre's goal of becoming a hub for community-based youth health research in the Interior.

"Youth health needs to be on the agenda," Ms. Clark said. "Community-based research works to increase that capacity."

Research network uses multidisciplinary approach to study self-injury in youth

Established by a 2005 CYHRNet Seed Grant, network emerges a leader in self-injury research and KT

It's a topic that's difficult to talk about – and difficult to comprehend.

Nonetheless, Dr. M.K. Nixon, team leader of the Interdisciplinary National Self-Injury in Youth Network Canada (INSYNC) knows it's important to try – and the team's multidisciplinary approach may be just the ticket to a greater understanding of youth self-injury.

"Self-injury crosses multiple areas," says Dr. Nixon, "so the great thing about our network is that it's multidisciplinary. We are addressing self-injury in a number of different settings and recognizing that it can present differently in each of these settings."

Established by a CYHRNet seed grant in 2005, INSYNC began with six members including a registered nurse and psychologist, a mental health research associate from an Ontario children's hospital, a psychiatry professor with expertise in neuroimaging as well as a researcher with a background in neuroscience.

Since then, the network has branched out to include a psychologist studying at

tachment and development related to self-injurious behaviours and a child and adolescent psychiatrist whose research interests include the developmentally delayed population and the neurobiology of self-injury.

Another recent recruit is a psychology PhD candidate whose dissertation examines risks and protective factors for non-suicidal self-injury in street-involved youth.

It's an important addition, says Dr. Nixon, as the self-injury research community is still quite small. Trainees' involvement in the network provides an excellent means both to expose them to existing expertise and to gain from their new research contributions.

The diversity of its members is also integral to INSYNC's pursuit of a holistic 'biopsychosocial' approach to understanding and treatment of non-suicidal self-injury in youth.

"Our intent is to broadly address this problem with the aim to broadly understand it as well," said Dr. Nixon. "I think we bring a richness of expertise."

It is an expertise the group is working hard to share.

"One of the big things we want to focus on is KT," said Dr. Nixon. "We have to translate this new research out into the community at large – not just to youth and their families but also to the practitioners working with these youth."

INSYNC KT Activities:

- Network website: www.insync-group.ca
- Publication of the book *Self-Injury in Youth: The Essential Guide to Assessment and Treatment* (called an 'indispensable reference' in an APA review)
- Membership in the International Network for the Study of Self-Injury: INSYNC will be sharing their work on an international stage at the next ISSS meeting at Stony Brook University in New York State.
- The development and provision of one-day workshops for mental health clinicians in Toronto, Ottawa and Revelstoke.