

newsletter

THE SLATE

The Office of Pediatric Surgical Evaluation and Innovation

VOLUME 4 • ISSUE 5

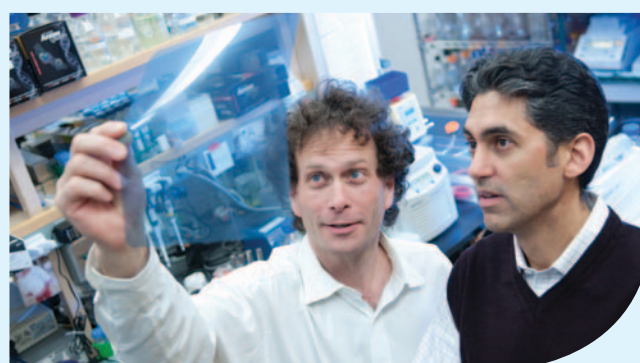
WINTER 2012



Partnership | Integrity | Enthusiasm | Achievement | Curiosity | Service



"OPSEI is committed to fostering an environment which creates opportunities for student and faculty partnerships in clinical research and education."



CONTENTS

OPSEI NEWS



» p.4



» p.14



» p.6



» p.9

3 iACT

The Innovations in Acute Care & Technology Research Cluster

4 PILOT PROJECT

Lights, Camera, Surgery - The Sequel 2011

6 SUMMER RESEARCH PROGRAM

Third ventricular shape: a predictor of Endoscopic Third Ventriculostomy success

7 Pediatric NSQIP

The Pediatric National Surgical Quality Improvement Program

9 SHARING THE CARE GLOBALLY

Pediatric Surgical Camp – Uganda 2011

10 TRAINING

The Pediatric Anesthesia Fellowship Program

12 ACCOMPLISHMENTS

The Department of Pediatric Orthopaedics

14 CLINICAL RESEARCH

The Rare Disease Foundation: Transforming Care

2011 iACT

TRAINEE CLINICAL INVESTIGATOR SEED GRANT AWARD RECIPIENTS



The Innovations in Acute Care & Technology (iACT) research cluster at BC Children's Hospital and the Child & Family Research Institute (CFRI) brings together basic, clinical, and population

health researchers in anesthesia, cardiology, critical care, emergency, and surgical specialties who share a common aim: to enhance the quality of care for children. Through wide-ranging research activities, they evaluate service delivery, address improved pain management, investigate molecular and cellular physiology in health and disease, study global health, and develop new technologies.

iACT was granted CFRI cluster status in April 2009. Since that time, members of iACT have maintained a close working relationship with the BCCH Office of Pediatric Surgical Evaluation and Innovation (OPSEI)

based on a shared commitment to ensuring that clinical practice questions drive research which in turn drives practice change. At the present time, the cluster has approximately 50 clinicians and investigators who have designated iACT as their affiliated cluster within the CFRI.



In August 2011, iACT awarded eight seed grants to help trainee researchers develop their capacity as clinical investigators. Below is a list of the grants awarded in 2011.

Trainee	Supervisor	Division/ Department	Title	Amount Awarded
Dr. Joseph Ting	Dr. Horacio Osioich	Division of Neonatology	Pharmacokinetics of phenobarbital in infants with hypoxic-ischemic encephalopathy during therapeutic hypothermia	\$4,600
Dr. Vikram Sabhaney	Dr. Quynh Doan	Division of Pediatric Emergency Medicine	Effect of Body Mass Index on the Risk of Fractures in Children	\$3,850
Dr. Zoe Brown	Dr. Stephan Malherbe	Department of Pediatric Anesthesia	Using Transesophageal Doppler to monitor changes in cardiac output and arterial blood pressure of pediatric patients prone for scoliosis repair	\$3,500
Dr. Kathy Lee-Son	Dr. Mina Matsuda-Abedini	Division of Pediatric Nephrology	Chronic Kidney Disease in Canadian Pediatric Non-Renal Solid Organ Transplantation	\$3,300
Dr. Nancy Vertel	Dr. Karen Campbell	Department of Pediatric Dentistry	Access to Dental Services for Children with Special Health Care Needs: A Pilot Study at BC Children's Hospital, Department of Dentistry	\$3,050
Dr. Bat-Chen Friedman	Dr. Ran Goldman	Division of Pediatric Emergency Medicine	Viral Etiology for Acute Wheezing Episodes in Children with High Risk for Subsequent Asthma	\$2,700
Mr. Devon Rasmussen	Dr. Sanjiv Gandhi	Division of Cardiovascular & Thoracic Surgery	Evaluation of Capacity for International Patient Care at BC Children's Hospital	\$1,700

Total iACT Trainee Clinical Investigator Awards \$25,115

Lights, Camera, Surgery - The Sequel 2011

KRISTIN DEGIROLAMO, STEVE RATHGEBER AND JENNIFER YAM

LCS Captains Summer 2011 | UBC Medicine Class of 2013

After a successful pilot and second season, the critics gave us the go ahead for a third season of Lights, Camera, Surgery! Film crews returned to the BC Children's Hospital campus in summer 2011 and worked behind the scenes to capture the spirit of pediatric medicine and surgery.

When UBC Medicine made the decision to expand their program and launch a distributed medical education program, thus creating new opportunities for clinical training throughout the Province of British Columbia, class sizes increased dramatically. Although this meant more students were given the opportunity to pursue medicine, this also posed new challenges. How could teaching be improved to span across all three teaching sites? How could teaching be done effectively and in a controlled setting to ensure that each student, regardless of site, would be given the same level of education?

Enter technology and the new age where education has evolved beyond paper textbooks in cramped libraries to online resources such as online textbooks, phone applications, online modules, Youtube...and online password-protected educational surgical videos? Yes! This is where Lights, Camera, Surgery (LCS) makes its grand entrance.

Funded by the UBC Teaching and Learning Enhancement Fund, Lights, Camera, Surgery is an initiative of the Office of Pediatric Surgical Evaluation and Innovation (OPSEI), with the mandate to create a library of instructional videos to be used for the teaching of basic surgical procedures. The goal of LCS is aimed at preparing medical students for their clinical years

using novel online resources. During the last 3 years of funding, LCS has been able to generate a modest collection of surgical and non-surgical videos with topics ranging from the simple surgical scrub technique, to procedures as complicated as scoliosis repair. While the videos produced serve as a great learning tool to introduce medical students in their pre-clinical years to the Operating Room Classroom, they have also provided the students who produced the videos an excellent

"The goal of LCS is aimed at preparing medical students for their clinical years using novel online resources."

opportunity to learn what really happens "behind the scenes".

The relationship between faculty mentors and students that develops during the production of videos has been crucial to the overall success of the project. The opportunity for junior medical students to engage in collaboration with staff physicians early in their careers is a valuable experience that will continue to benefit them as they progress through undergraduate training, residency, and beyond. These partnerships that develop during the summer often continue beyond the LCS program, resulting in publications and presentations at conferences in Canada such as the Halifax 10: The Canadian Healthcare Safety Symposium, the UBCMJ Research Forum and in the United States,

for the Western Medical Student Research Forum in Carmel. Of course the students are not the only ones to benefit from LCS. The faculty members involved have been extremely receptive to the project and have enjoyed working with all of the keen medical students to create educational and, on some occasions, humorous video resources. Although we believe the faculty when they say that they have enjoyed working with medical students on this project, we know that the elusive prize awarded at OPSEI rounds in October of every year for 'Best video' may be another source of their enthusiasm!

If you do not believe us, here is what some Faculty members and students have had to say about their experience with LCS.

1 Dr. Geoffrey Blair

"I was recently at an international film festival and reflected on how I think the LCS Project has afforded both the students and the mentors an opportunity to be creative and, yes, even artistic in the midst of the sea of facts, analysis and statistics that occupies the bulk of medical school. It has been a joy and privilege to work with all the students."

2 Dr. Neil Chadha

"This was my first year involved in the Lights, Camera, Surgery project and I found it rewarding and fun to work with the bright, enthusiastic, and receptive medical students involved. I hope that this interaction will have fostered an interest in surgery for some of those involved, as well as developing some very useful video resources."

Students are also enjoying their time with LCS. This project is unique in that it allows students to be involved in all aspects of the project while getting to shadow many different surgical specialties. It also gives the student an unique opportunity to be the mentor and teach the physician how to use video software to produce high quality educational films. Here is what a few of the students are saying about the project.

1 Anu Ghuman, UBC Class of 2013

"LCS provided me with a great introduction to the OR...it was fun, non-intimidating and overall a great experience. All the surgeons and staff we worked with at BC Children's Hospital were very nice and enthusiastic to teach students. I learned a lot about working as a team and the project has really opened my eyes to the possibility of pursuing surgery as a career."



From L-R Freda Wong, Kelvin Kwan, Lindsay McRae, Charmaine Ma and Kristin DeGirolamo at Carmel WSMRF 2010



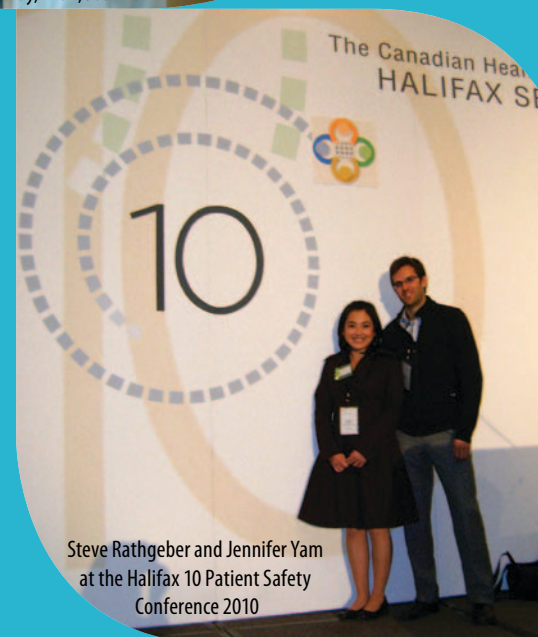
The LCS 2011 Team with Ms. Barb McKnight at a "learning how to scrub" session.
From L-R Meghan, Katherine, Barb, Indy, Evan, Joanne

2 Ida Molavi, UBC Class of 2013

"Lights, Camera, Surgery has been such an amazing and inspirational experience for me. To be given the unique opportunity of getting that much closer to the operating table as a second year medical student, while collaborating with renowned surgeons to produce educational videos is absolutely priceless."

As we wrap up the final year of funding for LCS, we are now moving towards promoting this valuable resource to students, residents and

faculty members. We are starting by putting posters up around BC Children's and Women's Hospital in study areas with links to the videos, as well as making presentations to the incoming UBC class so that students can take advantage of the 61 educational videos now available." We are also presenting the project at the Celebrate Learning Week at UBC from Oct 29-Nov 6, 2011 so that other faculties can learn from our model and hopefully incorporate similar programs into their schools.



Steve Rathgeber and Jennifer Yam
at the Halifax 10 Patient Safety
Conference 2010

Third ventricular shape: a predictor of Endoscopic Third Ventriculostomy success

ANDREW R WONG, MEDICAL STUDENT, UBC

Summer Student

This summer, I had the opportunity to work under the supervision of Dr. Cochrane in the Department of Neurosurgery at BC Children's Hospital. My project analysed the Endoscopic Third Ventriculostomy (ETV) – a treatment for hydrocephalus.

Hydrocephalus may present a number of ways in the pediatric population. Such presentations include: a full fontanel, headaches, nausea, vomiting, visual or developmental problems, irritability, or a failure to thrive.

Currently, two major treatments exist: ETV and VP shunting. Comparing the two, ETVs have a decreased risk of infection, over-drainage, blockage and are minimally invasive. Of interest to families, ETVs have also been shown to be less concerning for parents.

Despite the utility of ETVs, two questions remain: first, “Who are the best candidates?” and second, “Postoperatively, what is the best way to determine success?” We thought the answer may lie in medical imaging.

We performed a retrospective analysis on all children receiving an ETV at Children's Hospital from 2004 to 2010 and had both pre- and postoperative magnetic resonance (MR) head scans. It was hypothesized that, preoperatively, patients with an inferior bulging, or convexity, of the third ventricular floor (TVF) – into the interpeduncular cistern – and lamina terminalis (LT) anteriorly – into the interhemispheric cistern – would be good candidates for success. In addition, postoperatively, it was hypothesized that clinically successful patients would experience a resolution of convexity.

Both pre- and postoperatively, we assessed the presence of the above convexities (i.e. qualitative analysis) as well as created a new ventricular index – the Third Ventricular Morphology Index (TVMI) – to measure these convexities anatomically (i.e. qualitative analysis).

Upon analysis, 95% of successful patients exhibited the hypothesized convexities preoperatively. With that being said, 50% of those who did not display convexity also experienced success – demonstrating that while convexity



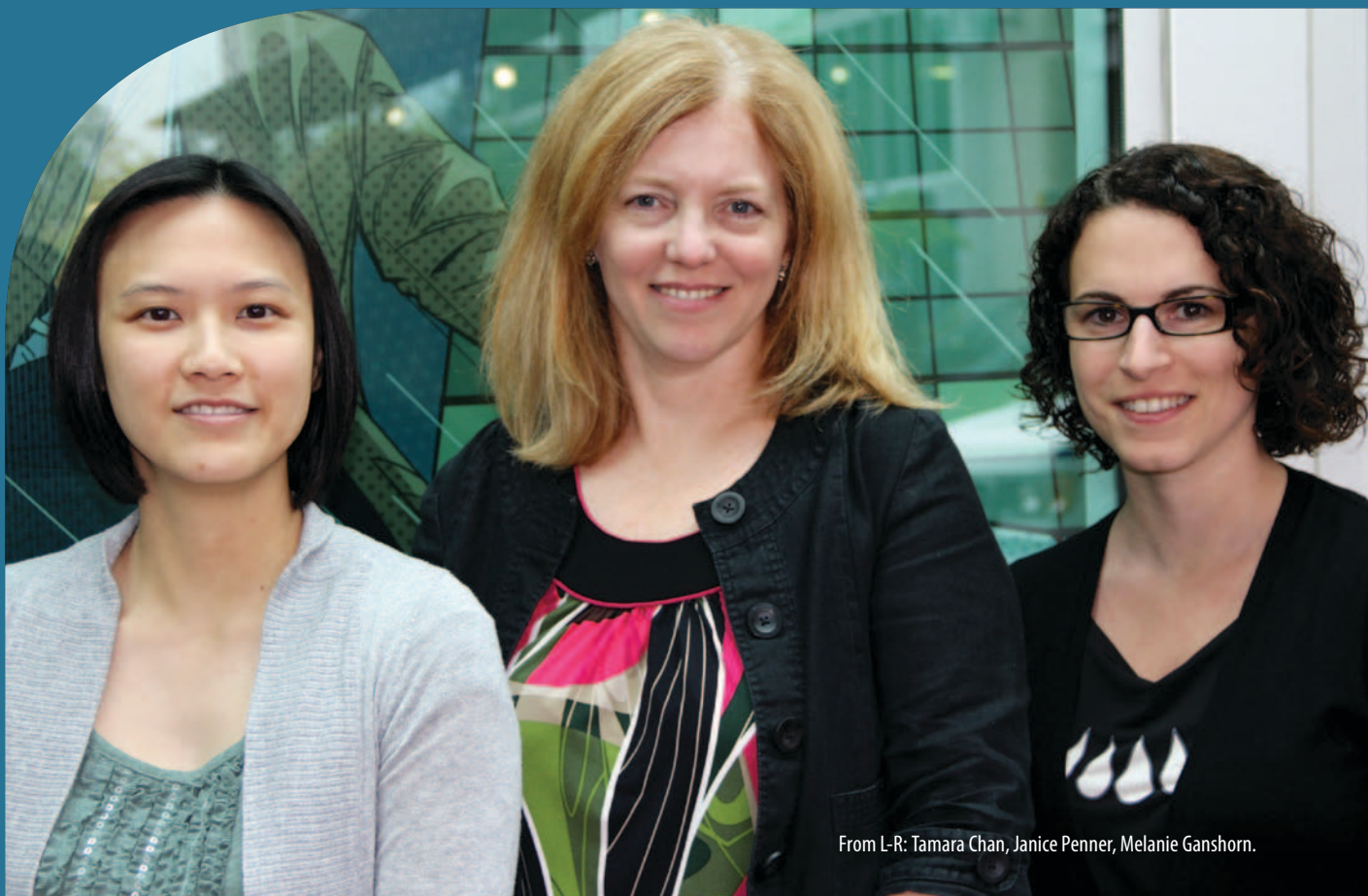
is a good predictor, it is not a necessary feature to possess. Considering our quantitative analysis, it was found that in all successful cases, the TVMI decreased postoperatively – consistent with convexity resolution. Of note, the TVMI

"I am truly grateful for the experience I had this summer to work at BC Children's Hospital. From an educational perspective, it was a very fruitful experience and I could not have asked for a better group of people to work with."

changes preceded and were of greater magnitude than those of the currently recognized “best” index: the Frontal and Occipital Horn Ratio. These findings add promise to the idea that analysis of third ventricular shape may provide a better predictive tool than current methods – aiding doctors and families in making the best decisions for children.

I am truly grateful for the experience I had this summer to work at BC Children's Hospital. From an educational perspective, it was a very fruitful experience and I could not have asked for a better group of people to work with. In addition to research, I was given the opportunity to attend the 54th Annual Meeting of the Society for Research into Hydrocephalus and Spina Bifida – hearing leaders in the field speak. I shadowed, met great people, became exposed to the life of a neurosurgeon...to a small degree... and hopefully, in the end, did some work that will help sick children and their families battling hydrocephalus.

BC Children's Hospital Joins NSQIP



From L-R: Tamara Chan, Janice Penner, Melanie Ganshorn.

In May 2011, BC Children's Hospital joined the Pediatric National Surgical Quality Improvement Program (NSQIP). This is a North American program run by the American College of Surgeons (ACS) currently involving 45 pediatric hospitals that collects and compares data related to surgical care of our patients.

Data is collected by a systematic sampling process and includes thirty-five surgical cases every eight days. Once the included cases are determined specific variables and definitions are applied to capture the data points correctly. The data points extracted include measurement from a patients' preoperative, intraoperative and postoperative phase. This program also follows the included patients for thirty days.

NSQIP has had great success with participating hospitals of reducing surgical mortality & morbidity, decreasing length of hospital stays and improving the quality of patient care.

BC Children's Hospital has two trained surgical clinical reviewers who will collect and validate data regarding surgical procedures. This will be entered into a secure

'NSQIP has had great success with participating hospitals of reducing surgical mortality & morbidity, decreasing length of hospital stays and improving the quality of patient care.'

website and reviewed so that surgical performance can be benchmarked with participating hospitals. Semiannual reports will be generated through regular reviews done by the ACS. Data will then be drilled down and analyzed to determine which processes can be improved.



"The Pediatric Surgical Camp was successful in improving the lives of over 200 Ugandan children and their families through the provision of high-quality surgical treatments"



Pediatric Surgical Camp – Uganda 2011

IN-KIND CONTRIBUTIONS FROM INDUSTRY PARTNERS

BC Children's Hospital shares in a long standing partnership with the University of Makerere, Uganda. As part of this ongoing collaboration a team of pediatric surgeons, anesthesiologists, nurses and support staff travelled to Uganda to participate in the Pediatric Surgery Camp in April 2011. The camp was welcomed by Dr. Doreen Birabwe-Male of Mulago Hospital, who is currently one of only two pediatric general surgeons serving Uganda's population of 30 million people. Working side-by-side, the Ugandan and Canadian teams provided invaluable surgical treatments to Ugandan children with a variety of surgical conditions during the camp. The successes of the camp also included contributions to training, education and local research relating to essential surgical care in low-resource settings.

In Uganda, children and their families face tremendous barriers in seeking treatment for even simple surgical conditions. These primarily include accessibility, local availability and costs of care. Camp services were all provided at no charge to families and were based out of hospitals in the capital city of Kampala and the rural Southwestern town of Ishaka. In low-resource settings such as Uganda even simple, treatable conditions such as pediatric inguinal hernia can lead to debilitating and even life-threatening complications due to the lack of basic surgical services. More complex conditions such as anorectal malformations lead to lifelong disability, suffering and stigmatization to children who are unable to access care. The children treated during the camp suffered from a broad spectrum of conditions including abdominal wall hernias, anorectal

malformations, Hirschsprung's disease and sacrococcygeal teratomas. The Pediatric Surgical Camp was successful in improving the lives of over 200 Ugandan children and their families through the provision of high-quality surgical treatments.

Education and research were central components of the Pediatric Surgical Camp which included residents of Anesthesia and Surgery from both Makerere University and the University of British Columbia. Ugandan surgical residents were mentored by Dr. Geoffrey Blair and the Ugandan anesthesia residents were mentored by Dr. Eleanor Reimer. Dr. Monica Langer (Fellow, Pediatric General Surgery, BCCH) employed video replay technology for teaching Ugandan surgical residents in technical procedures to maximize learning opportunities during the busy surgical camp. BCCH surgical nurses Cheryl Baldwin and Kat Lidstone worked closely with local nursing staff and led workshops on pediatric resuscitation and peri-operative care. The team also conducted a number of research initiatives that investigated barriers to accessing care and costs of providing essential surgical care in Uganda. The findings from the research provide important policy-relevant evidence that demonstrates the feasibility and cost-effectiveness of basic surgical care in low-resource settings.

The overwhelming success of the camp depended on the truly collaborative nature of the Ugandan-Canadian partnership. This symbiotic partnership provides tremendous opportunities for education, research and the delivery of clinical care. Most importantly the Pediatric Surgical Camp was able to provide life-changing treatments to children and families in need of surgical care.

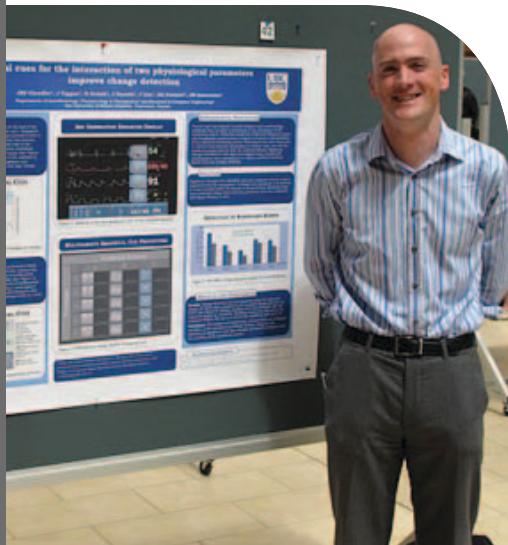


BCCH TEAM MEMBERS:

- Cheryl Baldwin, Nurse
- Kat Lidstone, Nurse
- Catherine Blair, Family Resource Volunteer
- Damian Duffy, Mission Coordinator
- Gareth Eeson, General Surgery Resident
- Dagmar Moulton, Anesthesia Resident
- Monica Langer, Pediatric General Surgery Fellow
- Eleanor Reimer, Pediatric Anesthesiologist
- Geoffrey Blair, Pediatric General Surgeon

THE CAMP WAS GENEROUSLY SUPPORTED BY THE FOLLOWING ORGANIZATIONS:

- Branch for International Surgery, UBC Resident Research Grants - G. Eeson, M. Langer
- Canadian Association of Pediatric Surgeons
- Donation from Dr. Tuan Pham + Family
- Donation from Mrs. Stella Perdios
- Donation from Mrs. Betty McGill
- Circle of Care Dr. and Mrs. Geoffrey and Catherine Blair
- Circle of Care Dr. Eleanor Reimer
- Ryerson United Church (medications and patient supplies)
- Donation from Mrs. Helen Prowse
- Donation from Kimberly-Clark



The Pediatric Anesthesia Fellowship Program

■ CJ MONTGOMERY

The Pediatric Anesthesia Fellowship has been functioning at BCCH since 1986, initiated by Dr. David Steward. There have been more than 60 Fellows during the last 25 years

We have 10 former Fellows who are now staff anesthesiologists: Drs Montgomery, Reichert, Reimer, Stephenson (newly retired), Ansermino, Scheepers, Purdy, Csanyi-Fritz, Whyte and Morrison. Other staff completed fellowships in organizations such as Boston Children's Hospital (Barker), CHOP (Froese), CHEO (Traynor), HSC (Goresky, Lee, Broemling), Seattle Children's (Bailey and Chen) Great Ormond Street (Lauder) and Stollery Children's Hospital in Edmonton (Malherbe).

Several members of our staff have also done additional extra training in pediatric cardiac anesthesiology including Drs Froese, Reichert, Lauder, Scheepers and Bailey.

Many of our recent fellows have established staff positions with internationally recognized pediatric hospitals such as Great Ormond Street, London, England (Helen Hume-Smith), Our Ladies Hospital for Sick Children, Crumlin, Dublin (John Chandler), Evelina Children's Hospital, London, England (Katherine Brand) and Royal Hospital for Sick Children, Edinburgh, Scotland (Emma Whyte, Jon McCormack and Gillian McFadzean)

This year we welcome Dr. Zoe Brown and Dr. Joy Sanders.

Zoe comes to us from the UK and completed her FRCA in 2009. She did a BSc in Physiology prior to her MD and, in addition to clinical research has managed to find time for travel in Australasia.

Joy also comes to us from the UK, qualified with her FRCA in 2008. She did a BSc in Anatomy and has over 5 years experience in anesthesiology. In May of this year, she worked in Global Health with Mercy Ships in Sierra Leone.

“The aim of the clinical training is to improve skills and confidence in managing the types of complicated pediatric cases that would be typically managed in a Speciality Centre.”

Typical of our Fellows, both are from the UK training system so they already have considerable clinical experience, are competent in performing routine pediatric cases with minimum supervision once they have been orientated to the Canadian system. The fellows also participate in a cardiac and PICU rotation. Additional experience in Acute Pain Management and ultrasound guided regional anesthesia techniques under the direction of Dr. Lauder is also a training goal.

The aim of the clinical training is to improve skills and confidence in managing the types of complicated pediatric cases that would be typically managed in a Speciality Centre.

The Fellowship is a combined clinical and research program and the fellows are expected to participate in clinical research.

Our fellows this year will be involved in projects:

- Examining the cardiac output in prone scoliosis patients
- Evaluating the effect of Dexmedetomidine given prior to induction as a co-induction agent and sedative.

In addition to developing a new project, the Fellows also are involved in completing previously initiated projects and in writing review articles and case reports.

There is also a tradition of the Fellows participating in Global Health projects. Most recently, Emma Whyte worked at Mulago Hospital in Kampala, Uganda last November. This year Zoe Brown is planning to go to Cambodia with Dr. Purdy and Operation Rainbow Canada in February. The Fellows are a valued and integral part of our department as they provide opportunities for diversity, innovation, research, teaching and learning.



The Department of Pediatric Orthopaedics

DR. KISHORE Mulpuri, PEDIATRIC ORTHOPAEDIC SURGEON

There have been many changes and accomplishments over the past year within the department.

The Pediatric Orthopaedic Research Group consists of Dr. Firoz Miyanji, Dr. Kishore Mulpuri, Dr. Chris Reilly, Dr. Christine Alvarez and Dr. Rick Beauchamp. This summer we welcomed Jeanie Zabukovec, MSc, to the research team as the new research coordinator. She joined us after completed her masters in Rehabilitation Science at UBC. Clint Hazen, research assistant, has now been with the team for a year, collecting data and recruiting participants for the numerous ongoing studies in the department.

Dr. Christine Alvarez's specializes in clubfoot and Hereditary Multiple Exostoses research and is assisted by Harpreet Chhina, MSc. Within the department we also have Dr. Ken Brown who specializes in research on musculoskeletal tumor removal in the extremities. We also collaborate with Alec Black in the Gait Lab at Sunny Hill Health Centre. Heather Macdonald, Assistant Professor in the department, has been away on maternity leave with her new born baby girl, Isla, and will be returning November 29th.

The department welcomed three new Fellows this year, Dr. Sinéad Boran from Ireland, Dr. Caroline Forsythe from Nova Scotia, and Dr. Sumit Gupta from Toronto. All three Fellows will be working with the team for a year, gaining clinical experience in pediatric orthopaedics.

With Dr. Christine Alvarez's expertise on Multiple Exostoses and clubfoot, she has had two papers submitted and accepted over the past year and was invited to present as the visiting professor at the 39th Annual Pediatric Seminar and Townsend Lecture in Alberta.

Dr. Beauchamp's expertise in gait has kept him busy writing a book chapter entitled "Normal and Pathological Gait" in Mercer's Text book of Pediatric Orthopaedics and Trauma. If you are a runner and want to keep up to date with techniques, equipment and injury prevention you can read Dr. Beauchamp's monthly "Sports Injuries" section in the Running Room Magazine.

Dr. Ken Brown had another successful year with the help of his research assistant Hyup Lee. Hyup was with Dr. Brown from January to June before entering medical school

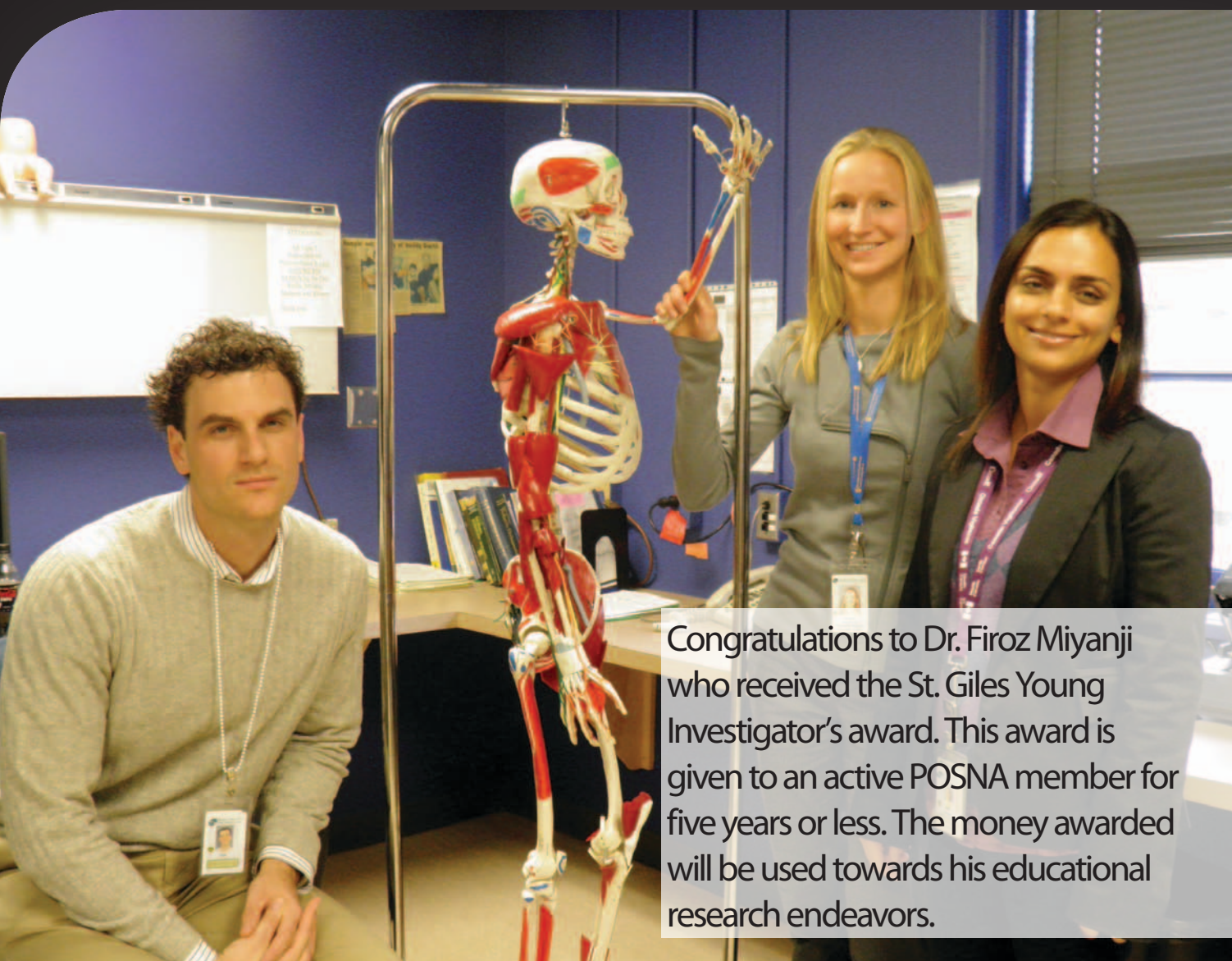
at UBC. Within 2011, Dr. Brown was on 4 editorial review boards of manuscripts, including Journal of Bone and Joint Surgery (American) and Journal of Pediatric Blood and Cancer, while teaching a section of the course entitled 'Clinical Skills - Musculoskeletal' for UBC medical students. Dr. Brown was also a study committee member on 7 randomized studies with the Children's Oncology group, which includes 236 institutions. He was a surgical reviewer on 4 of the 7 studies which kept him busy with committee conference calls, manuscript submissions and case reviews.

Congratulations to Dr. Firoz Miyanji who received the St. Giles Young Investigator's award. This award is given to an active POSNA member for five years or less. The money awarded will be used towards his educational research endeavors. With this, Dr. Miyanji was also appointed the POSNA Research Committee with Vice-Chair appointment for 2013. In the past year, Dr. Miyanji chaired the course "Advanced MIS Tutorial-MIS for Adolescent Deformity", held here at BCCH and the lab at UBC. Dr. Miyanji can be caught in action as a faculty participants in a "Lights, Camera, Surgery" film with the UBC medical students.

Over the past year Dr. Kishore Mulpuri has kept active in the clinical research world. He was the vice chair on the American Academy of Orthopaedic Surgeons (AAOS) treatment of pediatric supracondylar humerus fractures guidelines (<http://www.aaos.org/research/guidelines/SupracondylarFracture/SupracondylarFractureGuideline.asp>) as well as the chair of AAOS Developmental Dysplasia of the hip guidelines. Dr. Mulpuri was also recently appointed as the research director for the International Hip Dysplasia Institute (IHDI), which is a collaborative, international, not-for-profit effort to improve the health and quality of life of those affected by hip dysplasia (<http://www.hipdysplasia.org/default.aspx>).

Dr. Reilly, head of the Pediatric Orthopaedic department, recently presented at the 20th Annual G. Wilbur Westin lectureship at the Resident Academic Half-Day meeting in Los Angeles, CA.

Within the department we are currently recruiting for two randomized control trials. One study is looking at the treatment of supracondylar humerus fractures. The



Congratulations to Dr. Firoz Miyanji who received the St. Giles Young Investigator's award. This award is given to an active POSNA member for five years or less. The money awarded will be used towards his educational research endeavors.

other randomized control trial is investigating the use of a tissue adhesive, Demabond, versus surgical staples for wound closure and healing following surgical treatment of neuromuscular scoliosis. Other ongoing studies within the department include recruitment of patients with wrist fractures, adolescent idiopathic scoliosis, cerebral palsy, torticollis, and growth plate fractures.

Our department collaborates with many international research organizations including HARMS study group focusing on pediatric spinal deformities. Drs. Miyanji and Reilly are the only Canadian pediatric orthopaedic spine surgeons participating in this group. We also collaborate with IHDI, as well as research groups in India and Australia.

We also collaborate with the Gait Lab. The team at Sunny Hill consist of Alec Black (Director), Richard Beauchamp (Medical Director), Christine Alvarez (Co-Medical

Director), Jessica Maurer (Engineer), and Tanja Mayson, Valerie Ward and Karen Davies (Physiotherapists). Over the past year, Alec was awarded \$181,000 by the BC Children's Hospital Foundation and Sunny Hill Health Centre for Children Foundation for the upgrade of our Clinical Pressure Measurement systems as well as the UBC Orthopaedic Research Excellence Fund Award of \$25,000 for his study entitled "Rotational Profiles: Correlation between Computed Tomography and 3D Gait Measurements". Alongside attending conferences, workshops, and supervising students on research projects, Alec also created and validated a sleep assessment tool for children with Restless Legs Syndrome during this past year.

We are very proud of our academic accomplishments. In 2011 we had over 33 presentations at scientific meetings, 12 papers published, and an additional manuscript accepted.



The Rare Disease Foundation: Transforming Care



**RARE DISEASE
FOUNDATION**

DR. MILLAN PATEL

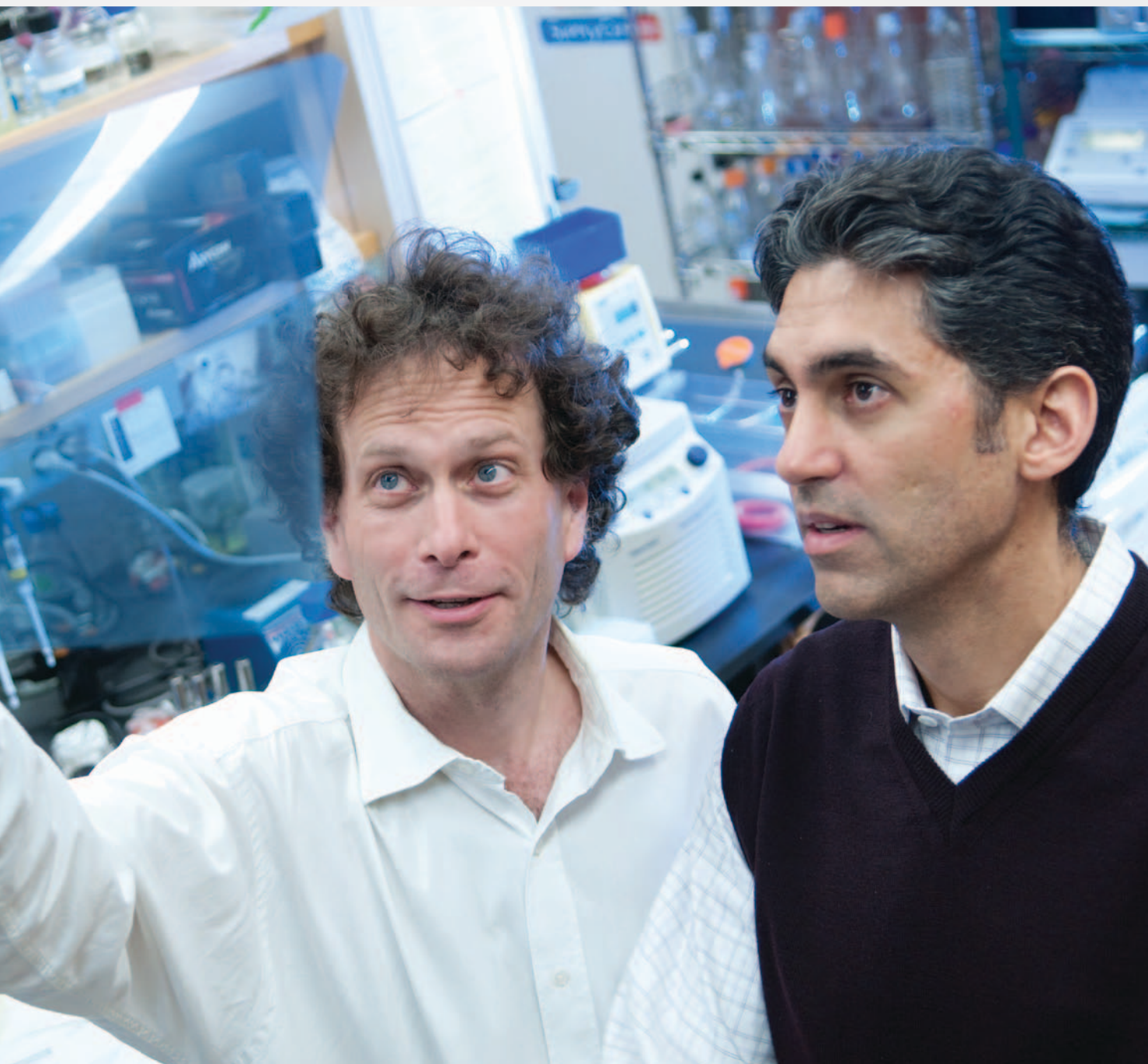
Frustrated by the number of rare disease patients they saw falling through the cracks and realizing that many patients could benefit from a small amount of additional research, Dr. Neal Boerkoel and Dr. Millan Patel decided to open a dialogue with physicians in 15 other divisions and departments on the Children's and Women's campus. What they discovered was a widespread pattern where physicians were using their own salary to support clinical research, driven mostly by compassion and curiosity. At the same time, several families affected by rare diseases had observed or benefited from this type of research and recognized that for their children, research is care. Together with Dr. Boerkoel and Dr. Patel, the families established the Rare Disease Foundation, whose vision is to transform the world of rare disease care.

The first program established by the Foundation was a microgrant program to provide funds (up to \$3500 at present) to support small clinical research projects that will directly benefit patients or their families. This program is off to a great start, with over 50% of applications funded and \$210,000 disbursed to C&W clinicians and researchers in the first 2 years of operation. It is being rolled out nationwide and has been warmly received in pediatric health research centres across Canada. Competitions are held every 6 months and will become more frequent as more funds are raised. The Rare Disease Foundation website (developed with generous support from OPSEI) provides follow up on how the microgrants had an impact. Dr. Ash Singhal of BCCH Neurosurgery has played a key role in the design and implementation of the microgrant program. BC Children's

Hospital Foundation also generously provided critical early support and guidance to get the Foundation off the ground. Most of the Rare Disease Foundation's funds are raised through annual events, including a skate-a-thon in the fall, the Diamond Race in early spring and a quirky but fun silent auction event, called Rare Finds, in late spring.

In the end, making a difference for families with one of the over 6000 known rare diseases will require the combined collaborative activity of academic pediatric medical centres worldwide. To model how this might work, the Rare Disease Foundation is in the early stages of creating a Health Professional Collaboratory. This would be a jointly shared laboratory with the infrastructure, both physical and personnel, in place so any health professional



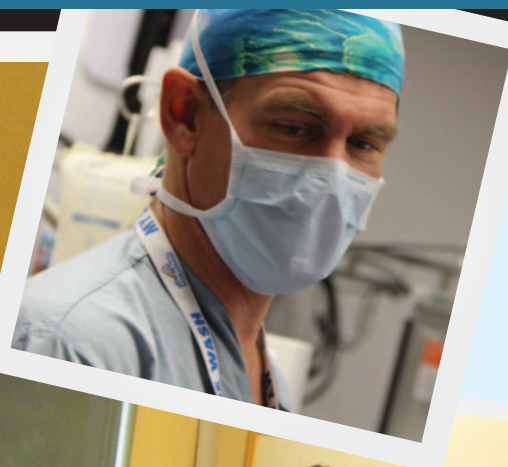


can follow up on an astute clinical observation or on a family's observation and bring the power of modern technology to bear for the benefit of patients. By removing the pressure of maintaining a laboratory infrastructure and combining the Collaboratory with research funding opportunities, the Rare Disease Foundation hopes to remove clinician scientists from the grant writing treadmill and leverage their intellects and passion to create greater patient impacts. The goal is to demonstrate the productivity of this approach and then advocate for exporting the model to other academic pediatric centres.

Thousands of rare diseases face a critical problem, diversity, which limits 'one size fits all' approaches to care. To address the diversity of problems facing families affected by rare conditions, the Rare Disease Foundation has

established an all-disease parent support group. Groups are organized locally to allow face to face meetings. The groups focus on problems that are common to many families, like the difficulty of negotiating a complex medical care system, obtaining government services or obtaining an aide for children in school. Each parent group invites special speakers and empowers parents by fostering mentoring of new parents or families in crisis by more experienced parents. The group format allows knowledge sharing regardless of disease type and gives meaning to the long and hard journey taken by many parents.

For more on how the Rare Disease Foundation is partnering with C&W, BCCHF, CFRI, OPSEI and other institutions in BC to transform rare disease care, visit their website at www.rarediseasefoundation.org.



Office of Pediatric Surgical
Evaluation and Innovation
BC Children's Hospital

Room K0-110 4480 Oak Street
Vancouver, BC V6H 3V4

