



RESEARCH INSTITUTE  
INSTITUT DE RESEARCH



# Transformation



Annual Report 2017-2018



uOttawa



Dear Friends,



## Message from the CEO

In addition to my role as the CEO and Scientific Director of the CHEO Research Institute, I'm also a pediatric emergency physician, treating patients and families with urgent care needs in CHEO's Emergency Department (ED). I'm extremely grateful to work alongside very caring and talented colleagues and continually impressed by their commitment to support the many research studies underway in the ED. They understand the importance of research in **transforming** the care we deliver by testing new treatments or developing new diagnostic tests. And the amazing thing is that this close integration between research and clinical care is not only in the ED but is happening in most areas of health care delivery throughout CHEO. As a physician it is so gratifying to see that we're using new techniques to treat common childhood injuries like wrist buckle fractures or concussion because of research projects that my colleagues and I were involved in. Research like this is transforming how I and many of my colleagues deliver the best care to children and youth here at CHEO, across the country and even around the world.

That's what research at CHEO can do – it can be **transformational**. It can transform the day-to-day practice of medicine at the individual patient level or change how we are organized to care for children across the health system. It can be a transformation at the health policy level, where evidence can inform how we approach issues as a society; and transformation can happen when we realize that the way to get a health discovery into the hands of so many more of the people who need it is through commercialization.

***Above all else, research can transform lives.***

Over the past five years, the CHEO Research Institute has been **transformed** as well, guided by our strategic plan, IMPACT 2018. We have seen significant growth in patient and family engagement in our research, we have seen improved integration of research throughout CHEO, our discoveries are being translated more and more often into patient care and we've been able to secure significant novel funding.

There's another transformation coming for the CHEO Research Institute and that is at the leadership level. I will be stepping down from my position as CEO and Scientific Director in June of 2019, the end of my second term at the helm of this wonderful organization. I have been so grateful over the past ten years to be part of the incredible community that makes up the CHEO Research Institute. From our institutional partnership with the University of Ottawa, Faculties of Medicine and Health Sciences to our local, provincial and federal partners, from our visionary funders and the patients and families who are at the heart of our research, I want to convey my sincere thanks for your role in how the CHEO Research Institute **transforms** care, policy, access and lives.

Thank you for your support,

**Dr. Martin Osmond**

CEO and Scientific Director, CHEO Research Institute

VP Research, CHEO





# Highlights from our Strategic Plan: IMPACT 2018

**Engaging Patients and Families:** A big part of engaging patients involves sharing information about research with patients and families. As part of our strategic plan we have been working hard to ensure that information about research currently taking place at CHEO is easily accessible to CHEO families. Our website now contains a search option so that families can look to see what research is happening in any area of interest. In 2017 we also began to focus on the need to share study results with families in a quick and easy manner. We launched the CHEO Discovery Minute program where researchers create a one-minute video to share the study results with participants.

**Integrating Research throughout CHEO:** Emergency Department (ED) research is one of the RI's most active research groups. Every day, ED staff support our investigators by connecting with patients and families who might be eligible for different research projects, which will lead to improved health. But we also knew that not all staff felt fully informed about the research happening in the department. A six-month pilot project called Research Matters shared short updates every two weeks about the different projects underway. ED staff reported loving the regular updates and feeling more informed about the department's many research studies. Due to the success of the program, Research Matters is now being rolled out to other areas of the hospital.

**Securing Novel Funding:** The Institute is focused on obtaining research funding from new and different sources as part of IMPACT 2018. A perfect example of this is the funding obtained by Sunita Venkateswaran and her research team from the Neurodegeneration with Brain Iron Accumulation (NBIA) Disorders Association for their study FAHN phenotype, lipidomic and proteomic signature aimed at better understanding of the clinical phenotype, MRI iron characteristics, and genetic spectrum of FAHN in children and adults and determine the effects of FA2H mutations on myelin structure and stability. Funding success from this association is a first for the CHEO RI!

**Translating Discoveries to Patient Care:** A new Permission to Contact Program is making it easier to connect CHEO researchers, patients and families. Patients or their caregivers visiting CHEO for treatment are asked whether they agree to have researchers contact them directly about studies they might be eligible to participate in. The response is recorded in the patient's electronic health record (EPIC). Contact for research participation may happen during or after their visit. Patients do not have to agree to studies they are invited to participate in and they can change their mind about participation in Permission to Contact at any time. The Permission to Contact Pilot began October 23rd, 2017 in the Endocrinology clinic; 85% of patients approached have agreed to participate in the program. Enabling researchers to directly approach agreeable patients and families through a hospital-wide Permission to Contact Program streamlines participation in research.

# Transformation

What does the investment of time, resources, energy and effort in research bring us? For the researchers, staff and partners at the CHEO Research Institute, it brings the opportunity to transform the lives of children, youth and families. New discoveries can transform how we deliver care – how we treat asthma, concussions or sleep disorders. Good policy is evidence-based and by building the body of evidence through research, we transform policy. When a discovery is made that could have a significant impact on the health of children and youth, naturally there's a desire to get that discovery out as widely as possible. However, there can be limitations on what can be done within a lab or how wide knowledge can go when it stays within the confines of a research environment. Transforming that research into a commercial entity could accelerate its benefits through increased investment and singular focus to take the discovery further. At the CHEO RI, we're proud of the transformations we've made in care, policy and commercialization.

## Transformation in Care

*The study showed that emergency department sedation for children is safe, with a low overall incidence of severe adverse events and interventions.*



## IMPROVING SAFETY IN SEDATION MEDICATION

A visit to the emergency department (ED) for a child can be worrying - a visit where a procedure requires sedation can increase the worry. Although ED sedation is regarded as safe, it has been associated with serious adverse events. Maala Bhatt and her research team, with the participation of six pediatric hospitals, conducted a large multicentre cohort study to improve understanding of the safety and comparative effectiveness of ED sedation. They were able to identify sedation medications and practices associated with the best clinical outcomes, which is practice-changing. The study showed that ED sedation for children is safe, with a low overall incidence of severe adverse events and interventions. The team also looked at the type of medication used in sedation with ketamine alone showing fewer severe adverse events and interventions than ketamine combined with either propofol or fentanyl. These findings will help reassure patients and families and guide staff in the ED on how best to sedate children.



## GETTING ASTHMA PATIENTS HOME EARLIER

Children hospitalized for asthma are able to leave the hospital earlier thanks to research done by Catherine Pound and her team. While nurses are responsible for monitoring these children, physicians used to be in charge of weaning children off the medication until children were ready to go home from the hospital. This was felt to lead to delays in weaning children from medication, and ultimately in being discharged, as physicians could sometimes be busy with sick patients. In their randomized controlled trial, the research team found that nurses could wean children off their asthma medication as safely and effectively as physicians. This relieved the pressure on busy physicians, improving the use of nursing resources. When asked about their experience, families reported a high satisfaction with the care received and felt that their needs were met.



## LISTENING IN TO IMPROVE TREATMENT

*Even if hearing loss seems “minimal” when first diagnosed, this research demonstrates the importance of close monitoring of children.*

Universal newborn hearing screening (UNHS) programs were introduced in Ontario in 2003 and have been essential in the early diagnosis of children who have hearing loss. But it's not enough to just provide a diagnosis. Also important is intervention, tracking the characteristics of childhood hearing loss over time and monitoring the effects of hearing loss on developmental outcomes. Elizabeth Fitzpatrick and her research team followed children who had been diagnosed with unilateral hearing loss over 13 years at the CHEO Audiology Clinic. About 40% of the children were at risk for further hearing deterioration and one in six progressed to bilateral hearing loss. Even if hearing loss seems “minimal” when first diagnosed, this research demonstrates the importance of close monitoring of children and good parent and caregiver counselling so that children have access to the supports they need. These supports may include amplification (e.g., hearing aids) and speech development work.





# Transformation in Policy



## TAKING CONSULTATION ONLINE

Access to specialist advice at CHEO was reduced to only one day from what could sometimes be a wait of weeks or months for face-to-face advice.

*Lillian Lai received The Innovation Fund Award for Technology and Education from IFPOC for the "eConsult" project*

Patients who needed to be referred see a specialist at CHEO would sometimes have to wait weeks or months to see them. Lillian Lai wanted to decrease the time it took for primary care practitioners to get specialist advice and developed a web-based consultation service research project. The service was the first of its kind for a Canadian pediatric tertiary care facility. Over the life of the research project, more than 1,000 "eConsult" requests from 367 primary caregivers were answered by 23 pediatric specialists representing 14 specialties, according to the study. The top three subjects were general pediatrics (36.9%), orthopedics (15.2%) and psychiatry (11.6%). Access to specialist advice at CHEO was reduced to only one day from what could sometimes be a wait of weeks or months for face-to-face advice. Primary care practitioners reported that, in over a third of cases, had it not been for "eConsult", they would have asked for a face-to-face referral, which would mean longer wait times for their patients. "eConsult" has been endorsed by the Ontario Ministry of Health and Long Term Care as a service that should be provided to the province and has committed budget to this make this a reality.



## THE WHOLE DAY MATTERS: 24-HOUR MOVEMENT GUIDELINES

How much sleep, movement and sitting time do children and youth need? How does each of these influence the other? How can this inform our public health policy? The Canadian 24-Hour Movement Guidelines, developed by our Healthy Active Living and Obesity research team, together with the Canadian Society for Exercise Physiology, ParticipACTION and other partners, take an integrative approach that sets out how much physical activity, sedentary behavior, and sleep children and youth should accumulate daily for optimal health. They are the world's first evidence-based guidelines that address the entire day. When looking at traditional health policy, most often there's a heavy emphasis on physical activity, without taking into account how children and youth spend the rest of their days. The Canadian 24-Hour Movement Guidelines look at the whole day and recognize the need for a more holistic way of thinking about how different movement behaviours throughout the day can influence the overall health of children. The guidelines help inform an inclusive and integrated approach in shaping health policy when it comes to raising healthy and active children and youth. New guidelines for children aged 0 to 4 years released this past year will also help support caregivers, educators, health professionals and others who help shape a young child's life.



## CAN SPECIALIZED INFANT FORMULA PREVENT TYPE 1 DIABETES? THE TRIGR STUDY RESULTS

*There is no need to develop separate feeding guidelines for infants who may have a genetic predisposition to Type 1 diabetes.*



A long-asked research question has finally been answered: is it possible to prevent Type 1 diabetes by altering the kind of formula that infants are exposed to in the first months of life? After 14 years, following 2159 children in 15 countries, researchers involved in the Trial to Reduce IDDM in the Genetically at Risk (TRIGR) study conclusively showed that altering the type of protein in infant formula does not affect the risk of developing Type 1 diabetes in children who had a family member with Type 1 diabetes. More than 25% of study participants were Canadian. The CHEO RI's Margaret Lawson and Brenda Bradley led the Canadian Coordinating Centre for the 18 TRIGR Canada sites. The study's conclusion will provide important guidance for those who are developing infant feeding policy and guidelines. There is no need to develop separate feeding guidelines for infants who may have a genetic predisposition to Type 1 diabetes and parents can feed their children the same way as any other infant.

# Transformation in Commercialization



## **TURNSTONE**

From bench to bedside - it's how we describe how research done in the lab can be used to develop treatments for patients. And while it's what we strive for, it's not a simple process. Clinical trials, where the safety and effectiveness of a new treatment in patients can be thoroughly tested, can be costly and take years. In many cases, discoveries may not make it off the bench because of lack of funding to take things forward. For many years, David Stojdl has been dedicated to finding better cancer treatments through oncolytic viruses. Together with his research partners John Bell and Brian Lichty, Stojdl knew that, in order to accelerate the development of their groundbreaking treatments, they needed significant financial investment. They established Turnstone Biologics in 2016 and received significant venture capital, in addition to a new licensing deal this past year with a major pharmaceutical firm. This will accelerate clinical trials and greatly increase the number of people who could benefit from immunotherapy in cancer treatment.



## **PRIVACY ANALYTICS**

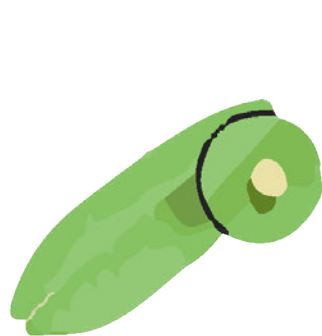
Electronic health information and access to health-related data is dramatically expanding health research opportunities. And while this is allowing researchers to greatly increase the evidence base, the need to maintain the privacy and confidentiality of patient information while doing so is key. Khaled El-Emam, Senior Scientist at the CHEO Research Institute, is a world-renowned expert in statistical de-identification and re-identification risk measurement. He understood the need for these skills outside of CHEO and one of the most sustainable ways to do this would be through the establishment of a private entity. Thus Privacy Analytics was born. The company has established a proven and responsible way to unlock the value in health data and works with the leading global agencies dealing with health information.



## SHOEBOX AUDIOMETRY

Hearing loss affects more than 500 million people globally and yet, for the majority of them, there is little access to the right tools to accurately test their level of hearing. This was one of the issues that Matthew Bromwich saw a solution to through Clearwater Clinical Ltd. Co-founded by Bromwich, a clinical investigator at the CHEO RI and a physician in the division of pediatric otolaryngology at CHEO, Clearwater acts as a medical technology incubator and has developed several products including SHOEBOX Audiometry. SHOEBOX is easy to use, clinically accurate and makes accurate and validated hearing tests much more accessible. SHOEBOX continues to grow in popularity with more than 100,000 people in 54 countries having used it. This past year, Clearwater received additional commercial investment to take its products further. Having SHOEBOX and other medical technologies available through a commercial entity has allowed Bromwich to build a team solely focused on taking his innovations further - refining them, finding markets and expanding access to them to as many people as possible, and allowed for other funding sources including grants and angel investments.

*Having SHOEBOX and other medical technologies available through a commercial entity has allowed Bromwich to build a team solely focused on taking his innovations further*





# Discovery Highlights

This past year, our researchers published 536 articles in peer-reviewed journals. From clinical practice guidelines to rare disease diagnosis, from mental health in the emergency department to the rural and urban divide in inflammatory bowel disease risk, the CHEO Research Institute's discoveries today are paving the way for healthier children and youth tomorrow.

## **Predictors of Repeated Visits to a Pediatric Emergency Department Crisis Intervention Program**

Canadian Journal of Emergency Medicine

P. Cloutier, N. Thibedeau, N. Barrowman, C. Gray, A. Kennedy, S.L. Leon, C. Polihronis, M. Cappelli

Repeat visits account for a large portion of all mental health presentations to the pediatric ED. Furthermore, several patient characteristics, including living in the metropolitan community close to the pediatric ED, being in the care of child protective services and taking psychotropic medications, are significant predictors of repeat pediatric ED use and of repeating sooner and more frequently. Further research is needed to examine interventions targeting this patient group to ensure appropriate mental health patient management.



## **Rural and Urban Residence During Early Life is Associated with Risk of Inflammatory Bowel Disease: A Population-Based Inception and Birth Cohort Study**

American Journal of Gastroenterology

Eric I Benchimol MD, PhD, Gilaad G Kaplan MD, MPH, Anthony R Otley MD, MSc, Geoffrey C Nguyen MD, PhD, Fox E Underwood MSc, et al on behalf of the Canadian

Gastro-Intestinal Epidemiology Consortium

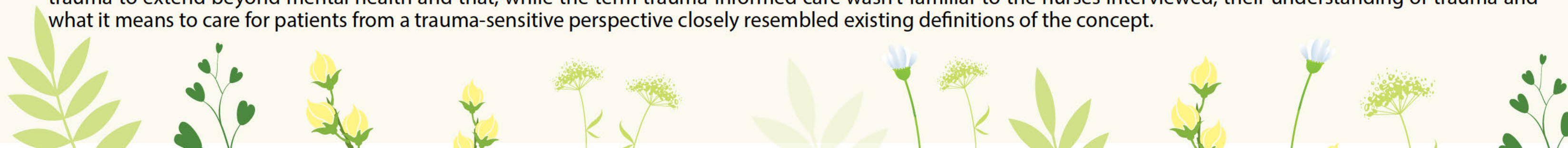
Researchers undertook two distinct studies to determine the association between inflammatory bowel disease (IBD) and an urban or rural household location. The first study looked at the IBD incidence and rural or urban residence when IBD was diagnosed; the second study looked at early life exposure to rural or urban environments and subsequent development of IBD. The research team found that people living in rural households had lower risk of developing IBD. This association is strongest in young children and adolescents, and in children exposed to the rural environment early in life. This suggests that early life exposure to environmental risk factors may more strongly contribute to the risk of IBD than exposure later in life.

## **Exploring Nurses' Knowledge and Experiences Related to Trauma-Informed Care**

Global Qualitative Nursing Research

Yehudis Stokes, Jean-Daniel Jacob, Wendy Gifford, Janet Squires, and Amanda Vandyk

Nurses are uniquely positioned to play an integral role in the advancement of trauma-informed care but knowledge related to this care in nursing practice remains limited. This qualitative study explored nurses' understandings and experiences related to trauma-informed care. Key findings include the need for knowledge about trauma to extend beyond mental health and that, while the term trauma-informed care wasn't familiar to the nurses interviewed, their understanding of trauma and what it means to care for patients from a trauma-sensitive perspective closely resembled existing definitions of the concept.





## **Annual and Seasonal Trends in Ambulatory Visits for Pediatric Concussion in Ontario between 2003 and 2013**

Journal of Pediatrics

Roger L. Zemek, Anne M. Groot, Daniel Rodriguez Duque, Carol De Matteo, Linda Rothman, Eric I. Benchimol, Astrid Guttman, Alison K. Macpherson

Pediatric concussion-related ED and physician office visit rates have greatly increased in the last decade, particularly since 2010. In this study, researchers looked to see if there was a seasonal trend in pediatric concussion and found that the greatest peak in the number of concussion-related visits occurred in fall and winter, with the lowest number of visits in summer. Prevention strategies may be targeted at those most at risk and at seasonal-related activities carrying the greatest risk of concussion.

## **International Cooperation to Enable the Diagnosis of All Rare Genetic Diseases**

The American Journal of Human Genetics

Kym M. Boycott, Ana Rath, Jessica X. Chong, Taila Hartley, Fowzan S. Alkuraya, Gareth Baynam, Anthony J. Brookes, et al

The International Rare Diseases Research Consortium (IRDiRC) was established in 2011 to bring together researchers and organizations invested in rare disease research to develop a means of achieving molecular diagnosis for all rare diseases. In this commentary, the group reviewed the current and future bottlenecks to gene discovery and suggested strategies for enabling progress in this regard. Each successful discovery will define potential diagnostic, preventive, and therapeutic opportunities for the corresponding rare disease, enabling precision medicine for this patient population.

## **Smac mimetics synergize with immune checkpoint inhibitors to promote tumour immunity against glioblastoma**

Nature Communications

Shawn T. Beug, Caroline E. Beauregard, Cristin Healy, Tarun Sanda, Martine St-Jean, Janelle Chabot, Danielle E. Walker, Aditya Mohan, Nathalie Earl, Xueqing Lun, Donna L. Senger,

Stephen M. Robbins, Peter Staeheli, Peter A. Forsyth, Tommy Alain, Eric C. LaCasse & Robert G. Korneluk

Glioblastoma is a primary brain cancer that can occur in both adults and children. When Smac mimetic compounds (SMEs) were combined with immune checkpoint therapy in mouse models, they showed that not only was it more effective than immune checkpoint therapy on its own, they also demonstrated a combination of therapies that could eradicate glioblastoma in this animal model.





# You are helping us Transform Lives

Funding for the CHEO Research Institute comes from a range of sources - from the community, through the strong support of the CHEO Foundation, academic partners, government agencies and ministries, the private sector, and other foundations.

*Thank you for your support.*



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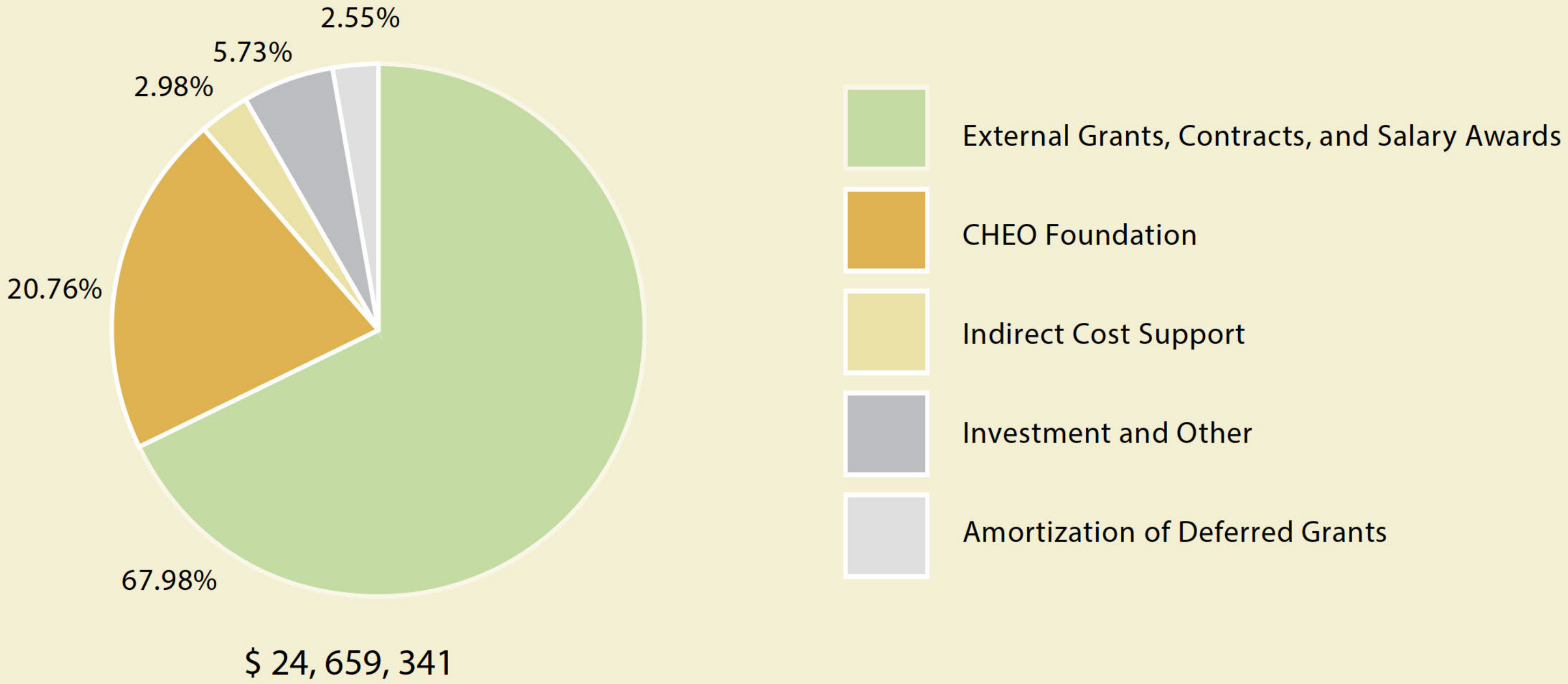




# Financial Statements (as of March 31, 2018)

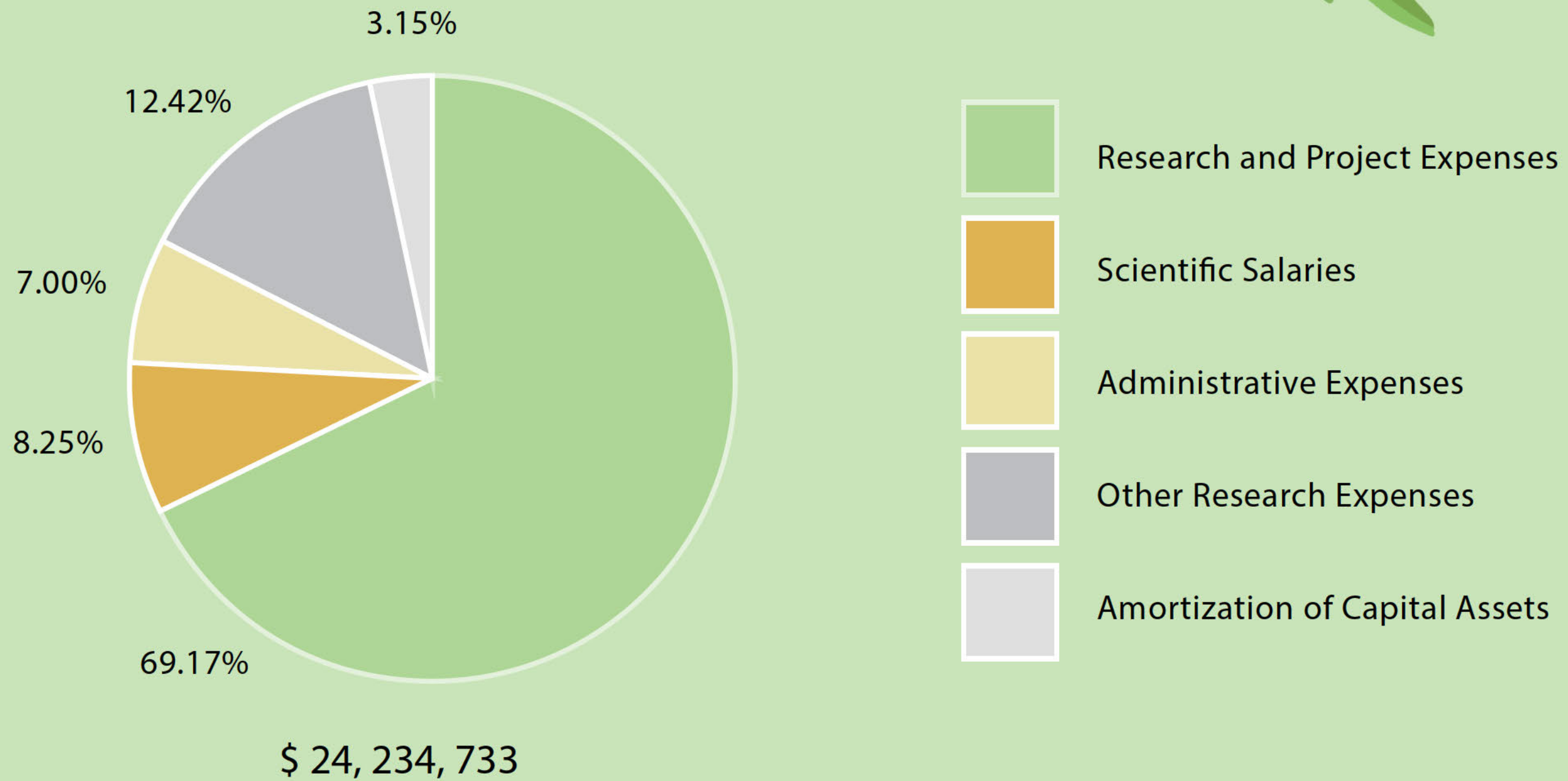


## Revenue Distribution 2017-2018





Expenditure Distribution 2017-2018





# Discoveries today for healthier kids tomorrow

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Martin Osmond, CEO and Scientific Director  
Rhonda Correll, Chief Operating Officer  
Chris St. Germain, Chief Financial Officer

## Mission:

We conduct innovative research in a dynamic learning environment and translate that knowledge into practice and policies to improve the health of children, youth and their families.

## Values:

Excellence  
Passion  
Integrity  
Creativity  
Collaboration



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