



# REPORT ON GIVING



PRESENTED TO

## **Mining for Miracles**



Since 1988, Mining for Miracles has contributed in excess of \$25,000,000 in support of innovative and lifesaving initiatives at BC Children's Hospital. Funds raised through annual events including the Diamond Draw, Teck Celebrity Pie Throw, Jeans Day™, Slo-Pitch, Hooked on Miracles Fishing Tournament, and numerous employee-led events add up to advance the mining community's collective efforts to make a difference in the lives of children across the province.



**DURING 2013 AND 2014**, Mining for Miracles raised \$2.66 million towards the establishment of Canada's first institutional pediatric biobank. The BC Children's Hospital BioBank opened in November 2014, and is facilitating breakthrough medical discoveries that will improve the lives of children suffering from debilitating and life-limiting diseases here and around the world.

# WHAT IS A BIOBANK?

**A BIOBANK IS A FACILITY** that collects and stores information (health data) and biological samples from many individuals. Biological samples stored at a biobank may include tissue, blood, saliva, urine, bone marrow or DNA. The BC Children's Hospital BioBank relies on donations of samples from children, youth, women and family members who are being treated BC Children's Hospital or at BC Women's Hospital.

Biobanks act as caretakers of these samples and data, safeguarding patient privacy and ensuring that samples are used for intended purposes.

## **What difference does a sample make?**

A single sample (blood, tissue, bone marrow, urine, saliva, or pregnancy-related tissues) from one patient has the ability to fuel up to five research projects, any one of which might lead to an important medical breakthrough. These samples are stored and made available to scientists around the world for research purposes.

## **How are samples processed?**

After a patient donates to the BC Children's Hospital BioBank, their samples are de-identified and processed in a laboratory where they are frozen, stored and continuously monitored. BC Children's Hospital BioBank staff enter information about the samples and information about the participant into a secure database. Patient confidentiality is protected by the BC Children's Hospital BioBank, and personal information is never released to anyone outside of the biobank.

Scientists submit applications to use biobank samples in their research. The application process includes a requirement for ethical review of the research project by a recognized ethics board.

### **How does it improve child health?**

The ultimate aim of the BC Children’s Hospital BioBank is to help advance science by providing the samples and information for developing new treatments, increasing the understanding of diseases, and finding the causes of specific ailments to improve and save the lives of children in British Columbia and around the world.

As a central repository or “bank” of data, researchers can borrow or withdraw information needed for their specific area of study.

For example, a researcher may be studying a form of childhood cancer. By studying the BC Children’s Hospital BioBank’s collection of samples, the researcher can delve into relationships between genes, the environment and lifestyles that play a role in cancer formation. From this, the researcher may be able to improve diagnosis, develop new treatments or provide prevention guidelines.

Once a research project concludes, findings related to specific samples are shared with the BC Children’s Hospital BioBank and the information is attached to the sample. The information can then be used in future research and any future information of those findings will also be attached. In this way, each sample in the bank “accrues interest,” in terms of information, and increases the wealth of knowledge the bank and samples contain.





“Thank you to everyone involved with Mining for Miracles! You have given researchers at BC Children’s Hospital the opportunity to drive scientific discoveries in pediatric care. It’s definitely an exciting time to be a researcher at BC Children’s Hospital.”

— Dr. Suzanne Vercauteren,  
Director of the BC Children’s Hospital BioBank

# PATIENTS BECOME PARTNERS IN RESEARCH

**AN IMPORTANT BENEFIT** of the BC Children’s Hospital BioBank is the impact on patients and families who are asked to contribute samples for research. Often, these patients and their families are experiencing some of the most overwhelming and uncertain moments in their lives. Almost 95% of families who are asked selflessly choose to participate in BC Children’s Hospital BioBank projects. Families and patients are grateful to have a way to contribute to finding new therapies, improving children’s quality of life and possibly discovering cures for the diseases affecting them so that other families won’t have to walk the same path in the future.

In addition, the BC Children’s Hospital BioBank offers children from around the province a way to contribute to research activities at BC Children’s Hospital thanks to new processes, which for the first time, allows the shipment of samples to the BC Children’s Hospital BioBank from across BC.

There are currently samples from over 500 different patients stored at the BC Children’s Hospital BioBank. This number will continue to grow in the future.





## CLARA'S STORY

**WHEN FIVE-YEAR-OLD** Clara Howorth's fever and flu didn't go away, and her temperature became dangerously high, her concerned parents took her to BC Children's Hospital's Emergency Department. Upon arrival, Clara was swiftly admitted to the Pediatric Intensive Care Unit to deal with a severe infection. Her family was shocked to learn a few days later that tests revealed Clara had leukemia, and she needed to start treatment right away.

*(From left to right) Brennan Howorth, Clara Howorth, BC Children's Hospital Foundation President & CEO Teri Nicholas, 2013/2014 Mining for Miracles Chair Jason Weber*

When asked if they would be willing to donate samples of Clara's blood and other biological specimens to the BC Children's Hospital BioBank, the Howorths didn't hesitate to sign the forms.

Over the next few weeks, Clara lived in the hospital and the toll of her treatments began to show: Clara lost her hair, and suffered from muscle weakness, bloating and many other side effects as a result of her medications.

Throughout Clara's treatment, the youngster and her family remained optimistic and today, Clara's cancer is in remission.

In April 2014, at age 7, Clara finished her two year treatment program, and celebrated with the hospital staff the completion of her cancer journey.

For Clara and her family, participating in research and the BC Children's Hospital BioBank program is a way to give back to BC Children's Hospital and express their immense gratitude to their oncology team.

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“Imagine if Clara's biobank contributions led to research discoveries that prevented another child from enduring chemo treatments, or long hospital stays or even helped find a cure... that would be truly amazing.”

—*Andrea Howorth, Clara's mother*

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# PROJECTS SUPPORTED BY BC CHILDREN'S HOSPITAL BIOBANK

**MINING FOR MIRACLES** has supported the BC Children's Hospital BioBank and, in turn, the biobank is supporting a variety of projects in areas such as oncology, hematology, and neurology.

Currently, sixteen research projects are supported by the BC Children's Hospital BioBank. These include:

- Analyzing the genetic code of leukemia. By examining genetic variances in more detail, researchers hope to pinpoint differences in genes that contribute to leukemia development and their response to current treatments.
- A new drug recently identified by researchers at Child and Family Research Institute (CFRI) as one that might be effective against leukemia. It shows the potential to activate the immune system to kill leukemia cells. Researchers need to find the best time during chemotherapy treatment to introduce this drug. The goal of the study is to determine when enough normal immune cells have returned to make the drug effective.
- Bringing advanced genetic technology to children with serious undiagnosed conditions in BC. The research program is known as the CAUSES research clinic and development is being supported by funds raised by Mining for Miracles in 2015/2016. Today, over 65 per cent of children admitted to BC Children's Hospital do not know the cause

of their illness. It is hoped that genome-wide sequencing will greatly increase the number of diagnoses, identifying rare illnesses caused by genetic disorders which could lead to further research into treatments. The CAUSES research team will share their findings through their involvement in national and international networks.

- Uncovering variations in genes which are associated with the cause of a patient's epilepsy. The project involves using a new genetic technology called next generation sequencing - specifically, whole exome sequencing (WES). WES looks at genes to find mutations that may be the cause of disease. When the cause of a child's epilepsy can be diagnosed early, doctors can avoid performing unnecessary and invasive procedures; earlier treatment will also reduce the harm of ongoing seizures in these patients. All results generated during this study will be presented to the BC Ministry of Health with a recommendation to make WES routinely available for children with epilepsy and seizure disorders.

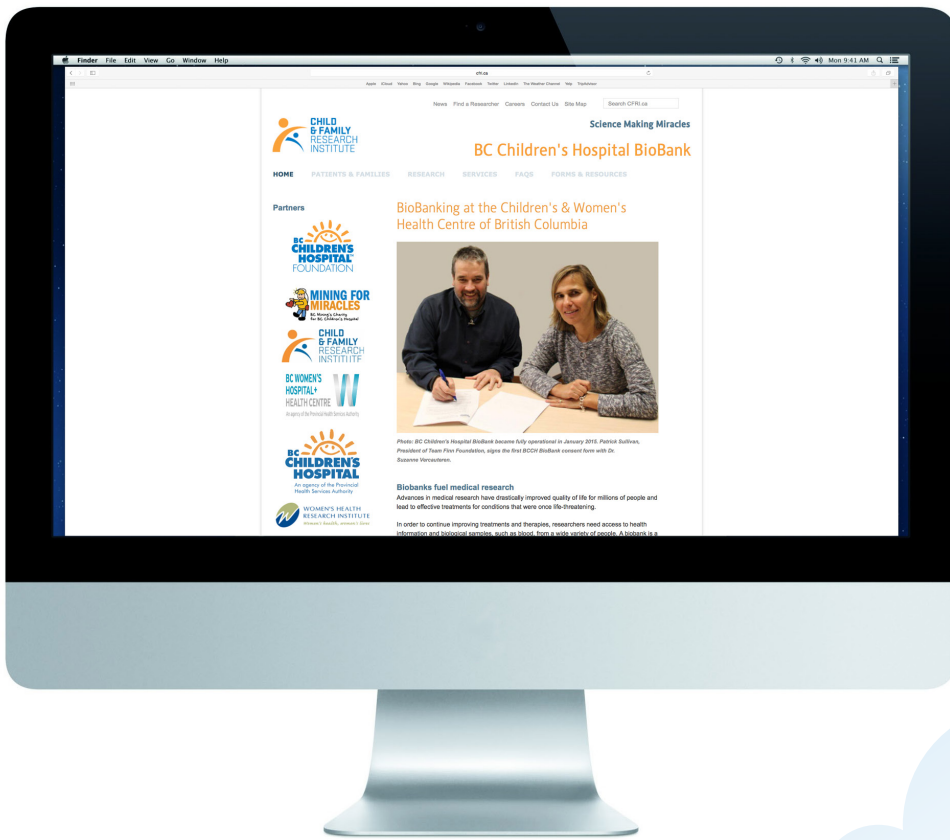
Success has already emerged from this study. Of 50 children whose genomes (collection of DNA) were sequenced as of June 2015, the cause of their epilepsy was identified in 13, and the results pointed to improved treatments for eight of them.

# NEW WEBSITE

**THE BC CHILDREN'S HOSPITAL BIOBANK** recently launched a website containing a wealth of information.

It's an in depth resource for patients, families and researchers as well as the general public interested in learning more about biobanks and how they enhance the world of research to the benefit of children in BC and around the world.

We invite you to visit the site at: <http://www.cfri.ca/biobank/>



# GROWING REPUTATION

**DR. SUZANNE VERCAUTEREN**, BC Children’s Hospital BioBank Director, and Tamsin Tarling, Administrative Manager, are actively seeking ways to grow the reputation and international presence of the BC Children’s Hospital BioBank.

A few recent opportunities taken to promote the BC Children’s Hospital BioBank include:

- Dr. Vercauteren presented at the 2015 International Society for Biological and Environmental Repositories (ISBER) on “Ethical Issues for Pediatric Biobanks”. Dr. Vercauteren’s ISBER presentation was so well received, Duke University asked her to present it as a webinar.
- In addition, Dr. Vercauteren and Ms. Tarling chaired an interactive discussion about the Ethical Issues Associated with Pediatric Biobanking.
- In July, 2015, Dr. Vercauteren led a presentation entitled Institutional Biobanks: How to Make Them Work at the Leaders in Biobanking Congress held in Toronto, ON.

By expanding its reputation and promoting research findings more researchers from around the world will seek out the samples and data collected at the BC Children’s Hospital BioBank to the benefit of children globally.



# THE FUTURE

**THE FUTURE OF THE** BC Children's Hospital BioBank is one of excitement, promise and possibilities.

As the province's only full-service acute-care hospital dedicated to children in British Columbia and the Yukon Territory, BC Children's Hospital is accessible to the largest population of children and youth served by a single Canadian hospital. Last year, more than 85,000 children made over 230,000 visits to the hospital.

With thousands of children being treated at BC Children's Hospital, and hundreds of clinicians and researchers dedicated to helping them, the demand for services offered by the BC Children's Hospital BioBank will continue to grow. For example, cardiac sciences and the department of surgery have recently expressed interest in working with the BC Children's Hospital BioBank in the coming year. Thanks to Mining for Miracles, the BC Children's Hospital BioBank will be ready to help.



# THANK YOU

**THE GENEROSITY OF MINING FOR MIRACLES** has created a legacy for future generations of researchers wanting to cure diseases, find new treatments and improve the health of others; and children and families looking for answers while facing devastating illnesses and conditions.

On behalf of BC Children's Hospital Foundation, hospital leadership, BC Children's Hospital BioBank staff, researchers and the children and families in need of scientific discoveries, we thank Mining for Miracles for its generous support.