Annual Report

BC Children's Hospital BioBank

APRIL 1, 2016 - MARCH 31, 2017

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1.0 Overview

This is the second annual report of the BC Children's Hospital BioBank (BCCHB), which has been operational since January 1, 2015 and made possible by a generous contribution from Mining for Miracles - the BC mining community's longstanding fundraising campaign for BC Children's Hospital. This report will cover operations and finance from April 2016 – March 2017.

The mission of the BCCH BioBank is to provide a comprehensive service for the collection, processing, storage, rapid access and retrieval of biospecimens and clinical information for research projects using a professional and compassionate approach to patient consenting that adheres to the highest standards of research ethics and patient privacy.

The BCCHB has a two pronged approach to supporting research, "general biobanking" and "PI driven research". In the general biobank specimens are collected under the mandate of the BCCHB for future research. For PI driven research the BCCHB provide researchers with specified services to enable their own research.

Pages 12 and 13 of this report refer to projects that have utilized specimens from the general biobank. The BCCHB Has released specimens to a range of projects from antibody research, immunity and responses to infections, cancer and rheumatic diseases.

Pages 14-16 describe the extensive list of PI driven studies that the BCCHB has been able to support over the last two years.

Below are data and other achievements from April 2016 - March 2017.

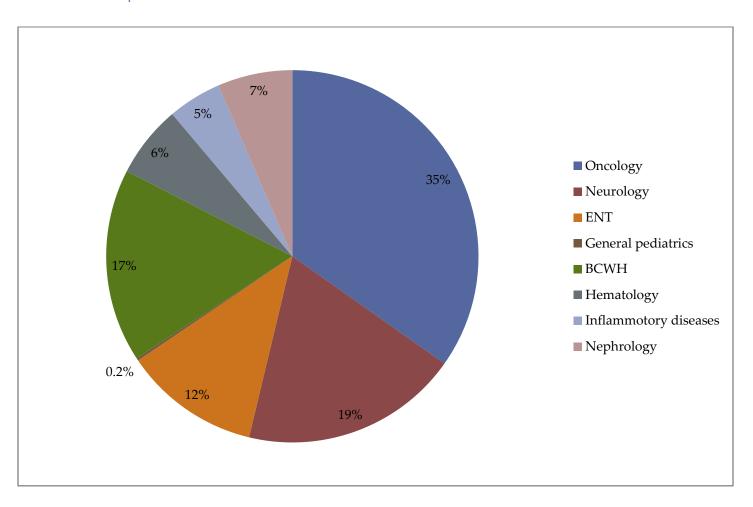
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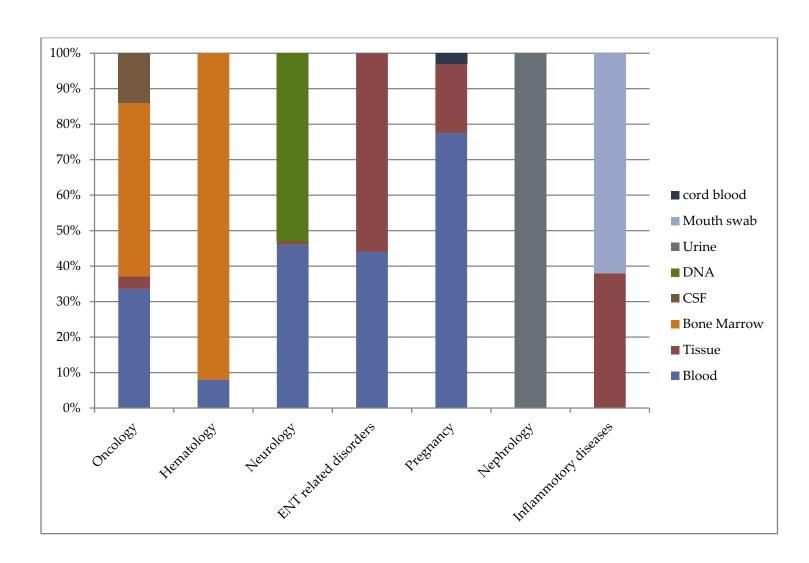
2.0 Participation Rate – General BioBank

	вссн	BCWH	Total (BCCH + BCWH)
Consent Obtained	250	60	310
Declined	7	9	16
Consent not completed	0	37	37
Withdrawn	0	0	0
Consent rate	97%	57%	85%

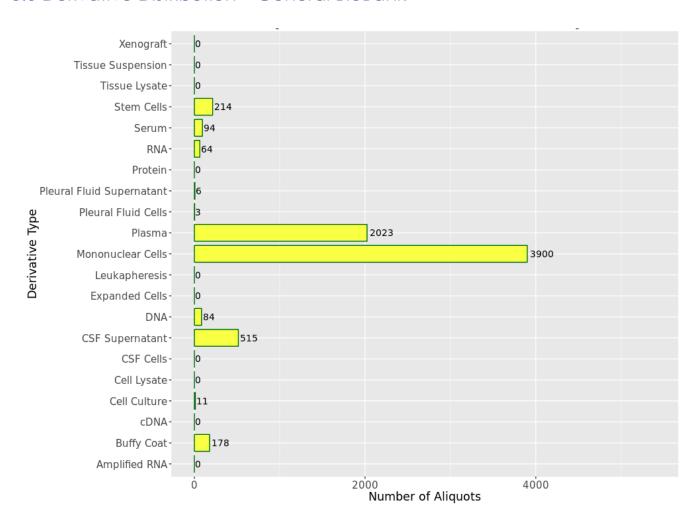
3.0 Clinic Representation – General BioBank



4.0 Specimen Distribution – General BioBank



5.0 Derivative Distribution – General BioBank



6.0 BioBank Oversight Committee (BOC)

Suzanne Vercauteren Chair of BOC	Director of BCCH BioBank
Mike Allard	Head of pathology and Laboratory Medicine, UBC
Kathryn Dewar	Senior Research Manager, WHRI
Ellen Giesbrect	Department of Obstetrics and Gynecology, UBC (BCWH Site Head)
Anne Junker	Representative for the Head of Pediatrics, UBC
Peter Watson	External Biobank Expert
Erik Skarsgard	Head of Department of Surgery at BCCH
Stuart Turvey	CFRI Director of Clinical Research
Mike Burgess	External Ethics Expert
Deborah McFadden	Head of Pathology and Laboratory Medicine at C&W
Anthony Bailey	Professor and Chair of Child and Adolescent Psychiatry, UBC
Tamsin Tarling	Administrative Manager, BCCH BioBank (ex-officio)

For the upcoming year:

Dr. Ellen Giesbrecht will be replaced by Dr. Julie Van Schalkwyk

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7.0 BioBank Executive Committee (BEC)

Suzanne Vercauteren Chair of BEC	Director, BCCH BioBank
Caron Strahlendorf	Member of Research Ethics Board
Wendy Robinson	Member of CFRI
Sheila O'Donoghue	Representative from OBER
Anna Lee	Pediatric and Perinatal Pathologist, Anatomical Pathology, BCCH
Tanya Nelson	Member of Pathology and Laboratory Medicine at C&W
Paul Yong	Member of WHRI
Gregor Reid	Member of CFRI
Tamsin Tarling	Administrative Manager, BCCH BioBank (ex-officio)

8.0 BioBank Biospecimen Advisory Committee (BAC)

William Gibson (Chair of BAC)	Member of CFRI
Suzanne Vercauteren	Director, BCCH BioBank
David Cabral	Member of BCCH
Helene Cote	Member of UBC
Jacob Rozmus	Member of BCCH
Amanda Skoll	Member of BCWH
Clare Beasley	BC Mental Health and Addiction Services
Isabel Jordan	Founder of Rare Disease Foundation parent advocacy group
Chris Dunham	Member of the Department of Pathology and Laboratory Medicine
Tamsin Tarling	Administrative Manager, BCCH BioBank (ex-officio)

For the upcoming year:

Dr. Chris Dunham will be replaced by Dr. Jefferson Terry.

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9.0 Staff

Suzanne Vercauteren	Director
Tamsin Tarling	Administrative Manager
Nidhi Arora	Senior Laboratory Technician
Thyrza May Toledo	Masters Student
Adam Velenosi	Research Assistant
Veronica Chow	Research Technician
Stephen Fung	Programmer/Analyst
Ashton Ellis	Research Coordinator
Heather Van Tassel	Co-op Research Assistant
Thomas Soroski	Work Learn Student
Mandy Suen	Undergraduate Laboratory Assistant
Rumbidzai Chiwaya	Undergraduate Laboratory Assistant

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10.0 Applications & Biospecimen Release

Between April 2016 and March 2017 the BCCH BioBank has received seven applications for biospecimens. Applicants and their research project titles are displayed below.

1. Carl Hansen (AbCellera, Vancouver, BC) – specimens granted (320 aliquots of mononuclear cells from tonsil tissue and 40 aliquots of mononuclear cells from blood)

High-throughput technology for human antibody discovery

Lay summary: AbCellera's platform is a powerful approach for human immune profiling. Partnering with the BC Children's Hospital Biobank has provided AbCellera with access to high quality patient samples that will better enable the discovery of next-generation monoclonal antibody therapeutics.

2. Herman Ziltener (University of British Columbia, Vancouver, BC) – specimens granted (2 crude tonsil extracts)

Assessment of alternate P-selectin ligand expression in human

Lay summary: We study adhesion molecules that initiate movement of white blood cells into tissues, a process that normally occurs during inflammation or in response to infection. These studies are part of a basic research effort to better understand mechanisms of inflammation and effective immunity. Access to human tissue, in our case tonsil samples, is important for assessing expression of such adhesion molecules in human white blood cells.

- 3. James Lim (BC Children's Hospital Research Institute, University of British Columbia, Vancouver, BC) specimens granted (116 plasma aliquots from bone marrow of leukemia patients)

 Monitoring serum calreticulin in pediatric ALL as a marker for positive chemotherapeutic response

 Lay summary: Calreticulin is a unique protein released by tumor cells that promotes the anti-tumor response by the body's own immune system. By analyzing calreticulin levels in the blood we hope we will be able to monitor a positive response to chemotherapy and have the potential to engage body's own anti-tumor activity.
- 4. Kelly Brown (BC Children's Hospital Research Institute, University of British Columbia, Vancouver, BC) specimens granted (3 CSF aliquots from Oncology patients with no CNS involvement and 3 serum samples from tonsillectomy patients)

Case Study of a Child with a Rare Auto Inflammatory Condition

Lay summary: Children with rheumatic diseases like juvenile arthritis have regular attacks of inflammation that can only be controlled by toxic drugs that have bad side effects. This research project aims to find biological markers to predict and assess these inflammatory attacks so doctors can more effectively customize treatment for each child.

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5. Kelly McNagny (Centre for Drug Research and Discovery, Vancouver, BC) – specimens granted (2 aliquots of mononuclear cells from bone marrow of leukemia patients and 2 FFPE scrolls mounted on slides) PODDO Study.

Lay summary: The primary samples provided by the BCCHB are indispensable tools to test an antibody which may have drug/diagnostic application in cancer as it specifically recognizes leukemic cells but not normal counterparts.

6. Philipp Lange (BC Children's Hospital Research Institute, University of British Columbia, Vancouver, BC) – specimens granted (33 aliquots of primary and mouse expanded mononuclear cells from bone marrow of leukemia patients and 15 aliquots mononuclear cells from blood of healthy patients and 2 FFPE scrolls) Proteins and their modification in childhood cancer.

Lay summary: When they are uncoiled, proteins are a long chain of amino acids that have a start and an end, called the termini. A process called proteolysis can cut proteins apart, creating fragments that have different termini. We have shown that termini found in cancer differ from healthy cells. The patient biopsies collected by the BCCH BioBank enable us to identify truly unique termini on leukemia cells and other pediatric cancers. Ultimately we hope to develop better targeted therapies with fewer negative effects for our small patients now or later in life.

7. Suzanne Vercauteren (BC Children's Hospital Research Institute, University of British Columbia, Vancouver, BC) – specimens granted (22 aliquots of plasma from solid tumour patients and 6 aliquots of plasma and 6 aliquots of stem cells from solid tumour patients)

Circulating Cell-Free DNA Analysis in Children with Solid Tumors Administered with Granulocyte Colony Stimulating Factor.

Lay summary: We are studying the effects of the drug called granulocyte colony stimulating factor (G-CSF), in cancer derived circulating DNA in the blood of children with cancer. Our research could impact the future use of G-CSF in treating some of the unwanted side effects of cancer treatments, and could provide a non-invasive way to detect the presence of residual tumors.

Over the period of April 2016 and March 2017, Dr. Gregor Reid requested more specimens for his study that was approved in 2015/2016:

Gregor Reid (BC Children's Hospital Research Institute, University of British Columbia, Vancouver, BC) – specimens granted (12 aliquots of mononuclear cells from bone marrow)

Prospective generation of pediatric leukemia relapse by xenotransplantation

Lay summary: Having leukemia cells in the bone marrow at the end of the first cycle of chemotherapy puts a patient at higher risk of the disease returning. As the BCCH BioBank has bone marrow samples from such children, we are attempting to grow the leukemia cells in order to determine what the potential relapse cells look like and what drugs they are sensitive to. This research could contribute to improving the outcome for children whose leukemia cells come back after treatment.

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11.0 PI Driven Studies

<u>#</u>	Study Name	<u>PI</u>	Services Provided	Sample Processing	# of collections or consents	<u>Storage</u>
1	SLED	Dr. Dina Panagiotopolous & Dr. Megan Levings	Receiving, labeling, recording, & processing the specimen	Serum Plasma Buffy Coat PBMC	324	- 80°C Liquid Nitrogen
2	Adult SLED	Dr. Jan Dutz	Receiving, labeling, recording, and processing the specimen	Serum Plasma Buffy Coat PBMC	4	- 80°C Liquid Nitrogen
3	Epilepsy & Genomics (EpGen)	Dr. Michelle Demos & Dr. Mary Connolly	Receiving, labeling, recording, and aliquoting the specimen	DNA Extraction	540	- 80°C
4	CAUSES	Dr. Jan Friedman	Receiving, labeling, recording, and aliquoting the specimen	Storage of whole Blood	429	- 80°C
5	SWAVE-U (study closed)	Dr. Jefferson Terry	Consenting patients and delivering the placenta to Anatomical Pathology	None	62	Store in the BioBank box in AP
6	mTOR	Dr. Rebecca Deyell	Receiving, labeling, recording, and processing the specimen	Protein Lysate (PBMC)	20	Temporary storage only (-80°C)
7	USTID	Dr. Jan Dutz	Receiving, labeling, recording, and processing the specimens	Serum Plasma PBMC Whole blood	186	- 80°C Liquid Nitrogen
8	Genome wide assessment of genetic alterations in pediatric acute leukemia (LBRWN)	Dr. Lindsay Brown	Consenting and data collection	None	543	None

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#	<u>Study Name</u>	<u>PI</u>	<u>Services</u> <u>Provided</u>	<u>Sample</u> <u>Processing</u>	# of collections	<u>Storage</u>
9	Understanding the risk of sudden death in families: cascade screening in CPVT (CARDIO)	Dr. Shubhayan Sanatani	Coordinating the collection of patient blood samples to FTA blood spot cards and storage	Blood spot card	28	Room Temp.
10	TREASURE (study closed)	Dr. Suzanne Vercauteren	Consenting	None	36	None
11	Vitamin B12 status in South-Asian and European pregnant women and their newborns (study closed)	Dr. Hilary Vallance	Labeling, recording, storage	None	n/a	- 80°C
12	Broady Lab	Dr. Raewyn Broady	Labeling, recording, storage	None	n/a	Liquid Nitrogen
13	Levings Lab	Dr. Megan Levings	Labeling, recording, storage	None	n/a	Liquid Nitrogen
14	A randomized controlled pilot study to examine the effects of goal-directed fluid therapy on postoperative outcomes in children undergoing scoliosis repair (study closed)	Dr. Zoe Brown	Labeling, recording, storage	None	n/a	- 80°C
15	Kingella Kingae	Dr. Ghada Al-Rawahi	Identifying eligible patients, deliver kits, consent patients	None	181	None
16	Overcoming the barriers to successful immune therapy for acute leukemia	Dr. Gregor Reid (Dr. Nina Rolf)	Consenting	None	55	None
17	PedVas	Dr Kelly Brown	Aliquoting, labeling, recording, storage	None	466	- 80°C Liquid Nitrogen Room Temp.

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<u>#</u>	Study Name	<u>PI</u>	<u>Services</u> <u>Provided</u>	<u>Sample</u> <u>Processing</u>	# of collections	<u>Storage</u>
18	AKI	Dr. Cherry Mammen	Processing, aliquoting, labeling, recording, storage	Urine (aliquoting)	75	- 80°C
19	EOE	Dr. Edmond Chan	Labeling, recording, storage	Freezing Tissue	88	- 80°C
20	TED	Dr. Linda Casey	Consenting and coordinating	None	1	None
21	POG cf DNA	Dr. Ryan Morin	Processing	Plasma Buffy Coat	208	- 80°C
22	BC-SICR	Dr. Srinivas Murthy	Labeling, recording, storage & processing	Whole blood aliquoting PBMC Plasma DNA	1	- 80°C Liquid Nitrogen
23	CAN-TBI Sub study	Dr. William Panenka	Labeling, recording, storage & processing	Plasma PBMC	134	- 80°C Liquid Nitrogen
24	STRIDER	Dr. Kenneth Lim	Labeling, recording, and storage	None	0	- 80°C
25	CROPS	Dr. Jan Dutz and Dr. Kevan Jacobson	Labeling, recording, storage & processing	Serum Plasma PAX gene PBMC	3	- 80°C Liquid Nitrogen

12.0 Key Performance Indicators (KPI)

	Key Performance Indicators	Jan 1, 2015 – March 31, 2016	April 1, 2016 – March 31, 2017
1	# of participants recruited	402	310
		27 per month	26 per month
2	# of requests for specimens from general biobank	4	7
		0.2 per month	0.6 per month
3	# of PI driven research projects supported	17	23
4	# of aliquots released from General BioBank	51	485
5	i) Mononuclear cells (post thawing) Recovery Viability ii) DNA A260/280 A260/230	62% 75% 1.84 1.93	90% 85% 1.86 2.20
6	# of successful grants for BCCHB specific projects	1	4
7	# of successful grants that proposed using BCCHB specimens/data	2	1
8	# of publications with BCCHB specimens/data	1	1
9	# of conference presentations/posters	7	4

13.0 Publications

BCCHB

- Nina Rolf; Kinga K Smolen; Amina Kariminia; **Adam Velenosi**; Mario Fidanza; Caron Strahlendorf; Alix E Seif; Gregor SD Reid. (2017). Absolute lymphocyte counts at end-of-induction correlate with distinct immune cell compartments in pediatric B cell precursor acute lymphoblastic leukemia. *Cancer Immunology and Immunotherapy*. Manuscript in revision.
- Brown Tony, Kelly Devon D., **Vercauteren Suzanne M.,** Wilson William H., and Werner Alexander. (2017). Biopreservation and Biobanking. How Biobanks Are Assessing and Measuring Their Financial Sustainability. *Biopreservation and Biobanking*.15(1): 65-71.
- Tamsin E. Tarling, Frances Lasser, Candace Carter, Lise A.M. Matzke, Gurm Dhugga, Nidhi Arora, Simon Dee, Jodi LeBlanc, Sindy Babinsky, Sheila O'Donoghue, Stefanie Cheah, Peter Watson and Suzanne M. Vercauteren. (2017). Business Planning for a Campus-Wide Biobank. *Biopreservation and Biobanking*. 15; 37-45.
- Kong CC, **Tarling TE**, Dittrick M, Strahlendorf C, **Vercauteren SM**. (2016). Opinions of Adolescents and Parents about Pediatric Biobanking. *Journal of Adolescent Health*. 58; 474-480.
- Tarling TE, Strahlendorf C, Schultz KR, Milner R, Vercauteren SM. (2015). Verbal permission to obtain clinically urgent biospecimens for a pediatric BioBank. *Journal of Clinical Research & Bioethics.*, 5; 202-209.

14.0 Grants (awarded in 2016/2017)

Operational

 Childhood Diseases Theme Platform Technology Grant (BC Children's Research), \$75,000 for one year. To increase utilization of the BioBank by CD theme members

Engagement and Education Research

- McGrail, Kimberlyn M, Burgess, Michael M; Meagher, Nancy L; O'Doherty, Kieran C;
 Vercauteren, Suzanne M. CIHR Project Grant, Filling the void: Public engagement around a new model for access to research resources. \$405,000 for 3 years.
- Evelyn Stewart, Jehannine Austin, Elodie Portales-Casamar and **Suzanne Vercauteren**. Michael Smith Foundation for Health Research Convening and Collaborating Award, \$15,000 for 1 year.
- Alice Virani, Ellen Chesney, Shazhan Ahmed, Patrick Sullivan, Isabel Jordan, Sheila
 O'Donoghue and Suzanne Vercauteren. CIHR Patient Orientated Research Grant: Giving
 patients and health care providers a voice in pediatric biobanking, \$25,000 plus \$20,000 form BC
 Children's Hospital Foundation for 1 year.

15.0 Presentations (2016/2017)

Poster presentations:

- Toledo, Thyrza May; Marwaha, Ashish; Velenosi, Adam; Townsend, Katelin; Arora, Nidhi; Bhullar, John; Tarling, Tamsin; Vercauteren, Suzanne (2016). Comparison of the Quantity and Quality of Mononuclear Cells Isolated by the Conventional Density Gradient Centrifugation Method versus Using SepMate Isolation Tubes for Biobanking Purposes. *International Society for Biological and Environmental Repositories (ISBER)* 2016 Annual Meeting, Berlin, Germany
- Rumbidzai A Chiwaya, Tamsin E. Tarling and Suzanne M. Vercauteren (2016). Exploring the strengths and weaknesses of ATiM Database to determine a flow path for its use on a daily basis. *Child and Family Research Institute Summer Studentship poster day.*

Oral presentations:

- Kristina Hill, Rebecca Pugh, **Tamsin Tarling**. International Society for Biological and Environmental Repositories (ISBER Regional meeting). November 2016. *Legal and Ethical Issues for Biospecimens*.
- **Suzanne Vercauteren.** January 2017. University of Alberta (webinar). *Implementing a Campus Wide Biobank*

Local:

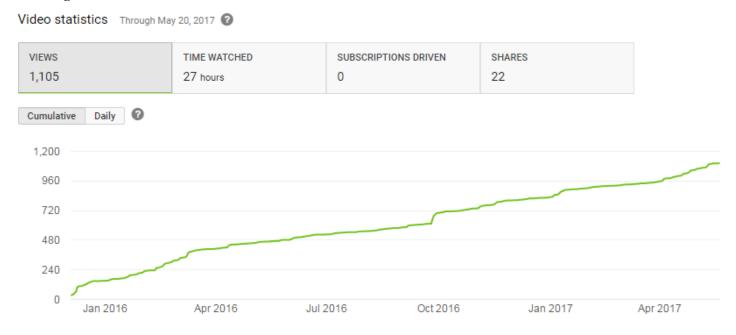
- Immunity, Health and Diseases. May 2016.
- BCWH OR Closure Day presentation. June 2016.
- BCCH Hem/Onc/BMT Fellows meeting. November 2016.
- Division of Neurology. November 2016.
- Surgical Cabinet Meeting. November 2016.
- TD Discovery Days. Tuesday, December 2016.
- BCWH Grand Rounds, January 2017.
- Brain Development and Behaviour, January 2017.

16.0 Communication

Our survey in Vancouver schools and BCCH clinics has found that public acceptance of biobanking in both adolescents and their parents is quite high after a brief education session. However, there is a limited number of people who actually know what a biobank is. The goal is to increase public awareness and education to build trust in the community and further contribute to the long-term success of the BCCH BioBank through increased enrollment. We continue to work on this engagement and education piece and there is an increasing interest in addressing this issue in the biobanking community at large. The BCCHB is very central to these discussions.

In the last annual report we highlighted the presence of BCCHB social media presence (Facebook and Twitter). Unfortunately the Provincial Health Service Authority (PHSA) requested that any social media relating to the BCCHB be posted via the PHSA social media outlets. In the past few months we have realized that this is an unsatisfactory solution and we are looking to re-launch our own social media presence.

Our YouTube video about the BCCHB has been viewed 1,105 times. The number of views is steadily increasing.



Website: www.bcchbiobank.ca

YouTube: https://www.youtube.com/channel/UCS1LxeGR]TRiejLRXw9heMw

BCCHB Newsletter: Summer 2016 & Winter 2016

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17.0 Financials

Income 2016/2017

Income from grants:	
CD theme	75,000.00
Brain Canada (pending)*	100,000.00
CIHR SPOR (pending)*	14,045.00
Income from services:	79,395.22
Total:	268,440.22

^{*}income due but not actually received

Full financial details for financial year ending March 2016

Toli ilitariciai actalis foi ilitariciai ye	Q1	Q2	Q3	Q4	Total
Opening Balance (\$)	1,230,956.63	1,166,579.50	837,486.12	686,221.49	10101
Funds Available (\$)	1,230,956.63	1,166,579.50	837,486.12	686,221.49	
Total Salaries (\$)	56,154.12	116,697.71	136,248.19	113,528.45	398,770.59
				-	_
Total Operating Expenses (\$)	8,223.01	209,002.98	15,016.44	46,593.34 + 2,821.56 (adj)	281,657.33
				-	
Total Expenses (\$)	64,377.13	325,700.69	151,264.63	160,121.79 (21,036.32)	680,427.92
Unexpended Balance (\$)	1,166,579.50	837,486.12	686,221.49	521.595	550,528.71
		-		-	-
Balance of grant account (\$)					64,620.00
Balance of income account (\$)					139,902.00
Available funds 2016/2017 (\$)					754,121.71
Predicted balance 2016/2017 (\$) (not accounting for in kind resources)					945,245.00

Comment on Financial status:

The BCCHB is currently sitting at \$191,123.29 less than predicted by the business plan for the end of the 2016/2017 financial year.

Below are some details to justify this:

- The BCCHB is waiting to receive \$100,000.00 income from Brain Canada
- The BCCHB is waiting to receive \$14,045.00 income from CIHR
- The BCCHB did not receive \$250,000.00 from a SPOR grant or equivalent due to lack of opportunities
- The BCCHB has not received \$10,000.00 from local Research Institutions (BCCHRI, WHRI)

In the coming months the BCCHB will be re-addressing the business plan budget to adapt to the current financial situation. It is normal for business plans to need refreshing after 4-5 years of operations.

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18.0 Abbreviations

REB – Research Ethics Board

BCCH – BC Children's Hospital
BCWH – BC Women's Hospital
PHSA – Provincial Health Services Authority
UBC – University of British Columbia
WHRI – Women's Health Research Institute

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19.0 Sign Off

Report compiled for the BCCH BioBank by:

Tamsin Tarling, BCCH BioBank Administrative Manager

Report reviewed by:

Suzanne Vercauteren, BCCH BioBank Director

Approved by:

BCCH BioBank Oversight Committee

Report signed off on behalf of the BCCH BioBank Oversight Committee by:

Suzanne Vercauteren, BCCH BioBank Director

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