Annual Report BC Children's Hospital BioBank

JANUARY 2015 – MARCH 2016

Annual Report

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1.0 Overview

This is the first 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. Our intention is for future annual reports to correlate with the financial year (April – March), however this report will cover operations and finance from January 2015 – March 2016.

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.

Below are data and other achievements from January 2015 - March 2016.

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2.0 Participation Rate – General BioBank

	вссн	всwн	Total (BCCH + BCWH)
Consent Obtained	258	144	402
Declined	28	13	41
Withdrawn	7	0	7
Consent rate	88%	92%	89%



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3.0 Clinic Representation – General BioBank



Solid tumour

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Benign blood

disorders

Epilepsy

■ Tissue ■ Bone marrow ■ CSF ■ DNA

ENT related

disorders

Pregnancy

4.0 Specimen Distribution – General BioBank

Leukemia and

lymphoma

Blood

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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)

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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)

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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
Jacquie Schein	Representative from Genome Sciences Centre (resigned)
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)

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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	Laboratory Assistant
Katelin Townsend	Research Technician
Stephen Fung	Programmer/Analyst
Mandy Suen	Co-op Research Assistant
Ashton Ellis	Co-op Research Assistant
Emma Valentino	Student Intern
Olive Zhu (until July 2015)	
Theresa Hinton (until October 2015)	



Suzanne Vercauteren Director



Katelin Townsend Research Technician



Adam Velenosi Laboratory Assistant



Tamsin Tarling Administrative Manager



Nidhi Arora Senior Laboratory

Technician



Masters Student

Emma Valentino Student Intern



Mandy Suen Co-Op Research Assistant



Ashton Ellis

Co-Op Research Assistant



Stephen Fung Programmer/Analyst

Thyrza May Toledo

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10.0 Applications & Biospecimen Release

Between January 2015 and March 2016 the BCCH BioBank has received four applications for biospecimens. Applicants and their research project titles are displayed below.

1. Jacob Rozmus – specimens granted (*3 aliquots of mononuclear cells from bone marrow*) TIDEX: A genomic study to identify new causes of treatable intellectual disability

2. Carl Hansen – specimens granted for proof of principle project (24 aliquots of mononuclear cells from tonsil tissue); full project is pending review.
High-throughput technology for human antibody discovery

3. Gregor Reid – specimens granted (*10 aliquots of mononuclear cells from bone marrow*) Prospective generation of pediatric leukemia relapse by xenotransplantation This was originally an application to the CCBR BioBank and specimens were granted, however Dr. Reid requested an additional specimen due to interesting initial results.

4. Connie Eaves – specimens granted (2 *aliquots of mononuclear cells expanded in a mouse xenograft model*) Origin and significance of altered DNA replication timing in pediatric leukemia

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11.0 PI Driven Studies

<u>#</u>	<u>Słudy Name</u>	<u>PI</u>	<u>Services</u> <u>Provided</u>	<u>Sample</u> <u>Processing</u>	<u># of</u> <u>aliquots/</u> <u>consents</u>	<u>Storage</u>
1	SLED	Dr. Dina Panagiotopolous & Dr. Megan Levings	Receiving, labeling, recording, & processing the specimen	Serum Plasma Buffy Coat PBMC	399 291 297 532	- 80°C Liquid Nitrogen
2	Adult SLED	Dr. Jan Dutz	Receiving, labeling, recording, and processing the specimen	Serum Plasma Buffy Coat PBMC	2 2 0 7	- 80°C Liquid Nitrogen
3	Epilepsy & Genomics (EpGen)	Dr. Michelle Demos & Dr. Mary Connolly	Receiving, labeling, recording, and aliquoting the specimen	DNA Extraction	430	- 80°C
4	CAUSES	Dr. Jan Friedman	Receiving, labeling, recording, and aliquoting the specimen	Storage of whole Blood	558	- 80°C
5	SWAVE-U	Dr. Jefferson Terry	Consenting patients and delivering the placenta to Anatomical Pathology		72	
6	mTOR	Dr. Rebecca Deyell	Receiving, labeling, recording, and processing the specimen	Protein Lysate	16	Temporary storage only
7	USTID	Dr. Jan Dutz	Receiving, labeling, recording, and processing the specimens	Serum Plasma PBMC Whole blood	648 648 1314 58	- 80°C Liquid Nitrogen
8	Genome wide assessment of genetic alterations in pediatric acute leukemia (LBRWN)	Dr. Lindsay Brown	Consenting and data collection		115	

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<u>#</u>	<u>Study Name</u>	<u>PI</u>	<u>Services</u> <u>Provided</u>	<u>Sample</u> <u>Processing</u>	<u># of</u> aliquots/ consents	<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	10	Room temperature
10	TREASURE	Dr. Suzanne Vercauteren	Consenting		29	
	Vitamin B12 status in South-Asian and European pregnant women and their newborns	Dr. Hilary Vallance	Labeling		127	Storage
12	Broady Lab	Dr. Raewyn Broady	Labeling		3800	Storage
13	Levings Lab	Dr. Megan Levings	Labeling		800	Storage
14	A randomized controlled pilot study to examine the effects of goal-directed fluid therapy on post- operative outcomes in children undergoing scoliosis repair	Dr. Zoe Brown	Labeling		70	Storage
15	Kingella Kingae	Dr. Ghada Al-Rawahi	Consenting		20	
16	Overcoming the barriers to successful immune therapy for acute leukemia	Dr. Gregor Reid	Consenting		64	
17	Brown Lab	Dr Kelly Brown			864	Storage

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12.0 Derivatives Associated with PI Driven Studies



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13.0 Key Performance Indicators (KPI)

# of requests for samples per year	4
# of requests for services per year	8
# of participants recruited between January 2015 and March 2016	402
Average # of participants recruited per month	27
QC of samples	DNA (average values for 54 samples, 10% of total collection) <u>Nanodrop ratios</u> 260/280 ratio = 1.84 260/230 ratio = 1.93 <u>Agarose gel</u> 1 out of 54 samples had some degradation (Omega Bio-tek method), all other DNA samples were intact in a 1% agarose gel. Viable Cells from thawed PBMCs Average Recover = 62%
	Average Viability = 75%

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14.0 Publications

BCCHB

- Kong CC, Tarling TE, Dittrick M, Strahlendorf C, **Vercauteren SM**. 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.

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15.0 Presentations

Poster presentations:

- Tarling TE, Kong C, Dittrick M, Zhu O, Vercauteren SM. Opinions of Adolescents and their Parents from the General Public Regarding Common Topics in Pediatric Biobanking. Canadian Association of Paediatric Health Centres 2015.
- Kong C, Tarling TE, Dittrick M, Milner R, Strahlendorf C, Vercauteren SM. Opinions of Adolescents and their Parents Regarding Common Topics in Pediatric Biobanking. ISBER 2015.

Oral presentations:

- 7th International Leaders in Biobanking Congress. July 14-16, 2015
 - Brainstorming session moderator. Institutional Biobanks: How to Make Them Work.
 - Specialty Biobank Podcast and interactive session moderator: *Planning and Implementing an Institutional Biobank for Children and Women: Ethical and Operational Considerations*
- International Society for Biological and Environmental Repositories (ISBER) 2015. May 2015. Interactive discussion facilitator. *Ethical Issues for Pediatric Biobanks*
- ESBB Annual Conference. September 29 October 2, 2015. *An evaluation of international methods of public engagement and their local suitability*

Local:

- Gairdner High School Symposium. October 26th, 2015.
- TD Discovery Days. Tuesday, December 1st, 2015. An interactive session where students learned why biobanks are important and how biological specimens are processed and stored for future research.

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16.0 Communication

In fall of 2015, we have made an effort to increase our presence on social media through various mediums. 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.

After receiving approval through the REB, we created an educational YouTube video aimed at children and their parents to help achieve a better understanding of how the BioBank works. In the future, we hope to create additional videos aimed at both adolescents and pregnant women, respectively.

Website: <u>www.bcchbiobank.ca</u> Facebook: <u>https://www.facebook.com/bcchbiobank/</u> Twitter: <u>https://twitter.com/BCCHBioBank</u> YouTube: <u>https://www.youtube.com/channel/UCS1LxeGRJTRiejLRXw9heMw</u>

BCCHB Newsletter: <u>Winter 2015</u> & <u>Spring 2016</u> UBC Pathology Newsletter: <u>Summer 2015</u> pg.44

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17.0 Financials

Summary of financial activity year ending March 2015

2013/2014 Predicted Expenditure (\$)	2013/2014 Actual Expenditure (\$)	2014/2015 Predicted Expenditure (\$)	2014/2015 Actual Expenditure (\$)	Total Predicted Expenditure (\$)	Total Actual Expenditure (\$)	Expenditure Balance (\$)
1,018,500	142,172	336,500	818,846	1,355,000	1,155,346	1,701,577
2013/2014 Predicted Income (\$)	2013/2014 Actual Income (\$)	2014/2015 Predicted Income (\$)	2014/2015 Actual Income (\$)	Total Predicted Income (\$)	Total Actual Income (\$)	
-	-	16,000	17,555	16,000	17,556	
					Predicted balance at end of 2014/2015 (\$)	Actual Balance 2014/2015 (expenditure balance + income) (\$)
					967,500	1,719,133

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Full financial details for financial year ending March 2016

	Q1	Q2	Q3	Q4	Total
Opening Balance (\$)	1,701,577	1,618,123	1,507,297	1,450.986	1,701,577
Money Received (\$)	3,393			651	4,044
Funds Available (\$)	1,704,967	1,618,123	1,507,297	1,451,637	1,705,621
Total Salaries (\$)	43,154	42,991	103,827	201,817	391,790
Total Operating Expenses (\$)	43,693	4,835	15,484	23,003	87,015
Total Expenses (\$)	86,847	47,826	119,311	224,821	478,804
Unexpended Balance (\$)	1,618,123	1,570,297	1,450,986	1,226,816	1,226,816
Income from services 2014/2015 (\$)					17,556
Income from services 2015/2016 (\$)					48,536
Final balance 2015/2016 (\$)					1,292,908

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18.0 Abbreviations

BCCH – BC Children's Hospital UBC – University of British Columbia WHRI – Women's Health Research Institute REB – Research Ethics Board

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19.0 Sign Off

