



BRCAinBC: Strategic Plan, Achievements & Directions 2018 - 2024

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Strategic Plan

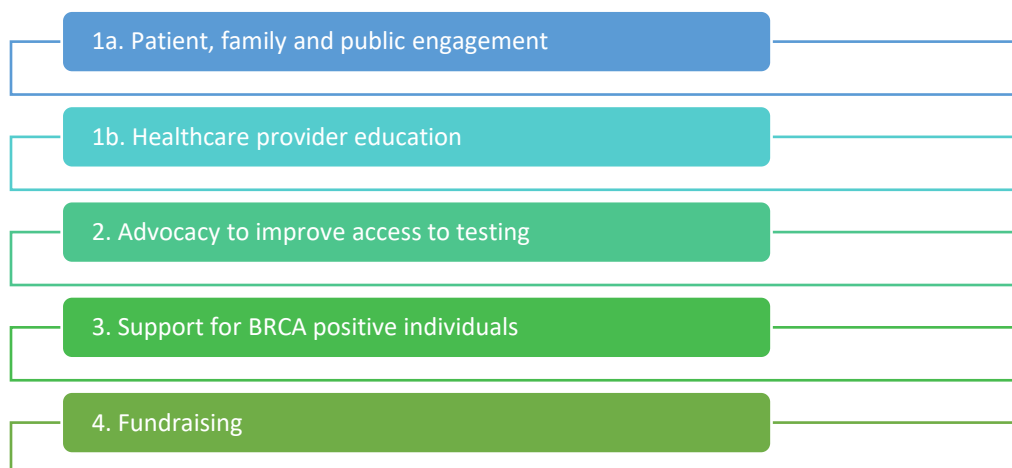
Who is BRCAinBC?

BRCAinBC is made up of a group of individuals concerned about the effect of the BRCA genes on the Jewish community in British Columbia. The group is comprised of passionate community members who have been personally affected by the BRCA genes, medical and health professionals and researchers, experts in genetic cancers, health promotion professionals, Jewish advocacy professionals and community leaders. Our work has been supported by a number of generous organizations, institutions and members of the community, including the BC Cancer 's Hereditary Cancer Program High-Risk Clinic, UBC's Gynecological Cancer Initiative, VCH's Gynecological Cancer Prevention and Survivorship Clinic, Congregation Beth Israel, Vancouver Talmud Torah, the Jewish Federation of Greater Vancouver, the Znaimer Family Foundation and the Diamond Family Philanthropic Fund as well as many private citizens and donors.

What does BRCAinBC do?

This project was born out of the recognition that many members of our Jewish community in BC were unaware of the elevated risk of carrying a BRCA gene for Ashkenazi Jews and the risk of genetically-linked cancers. The work we have done intends to improve awareness of the risk and the need for testing among community members and BC medical and health professionals, educate community members about genetic testing options and will reduce the fears and stigma that can surround genetic testing. We are also working to improve access to genetic testing for all members of the Jewish community, not just those with a family history of cancer and improve supports for members of the community who ultimately test positive for a BRCA gene. Ultimately, this group believes that knowledge is power.

Core Areas of Work



Underlying Principles of BRCAinBC

BRCAinBC is guided by health promotion principles, including: **Empowerment** (a way of working to enable people to gain greater control over decisions and actions affecting their health), **Participatory Action** (where people who are affected by decisions are actively involved in making those decisions), **Holism** (taking account of the separate influences on health and the interaction of these dimensions), **Equity** (ensuring that underserved groups or groups with barriers to engagement are involved), **Intersectoral** (working in partnership with other relevant agencies/organisations), **Sustainable** (ensuring that the outcomes of health promotion activities are sustainable in the long term), **Multi Strategy** (working on a number of strategy areas such as programs or policy). The World Health Organisation took a leading role in action for health promotion in the 1980's with the Ottawa Charter being published in 1986. It suggested that health promotion happens at five key levels.

- Developing Personal Skills
- Creating Supportive Environments
- Strengthening Community Action
- Developing Public Policy
- Re-orienting the Health Services

It is through an analysis of these principles and key levels of action, that BRCAinBC developed our 4 Primary Pillars.

BRCAinBC 4 Primary Pillars

1. Pillar 1: Improve community education and awareness of the BRCA genes in the BC Jewish community and among the BC medical professional community.
2. Pillar 2: Provide political advocacy to improve access to genetic counselling and testing for the BC Jewish community.
3. Pillar 3: Improve or create better support for members of the Jewish community who test positive for a BRCA gene.
4. Pillar 4: Fundraise to support these various goals and initiatives.

Potential Additional Pillar (defined in August of 2022): Improve access to and education about surgical options for BRCA positive individuals in BC.

Theory of Change

Our approach to the work at BRCAinBC is influenced by the principles of dialogue as a mechanism for community and health systems change. Dialogue on health systems change is particularly important due to the multiplicity of complex issues and perspectives on personal and community health and wellbeing – including individual needs, systems resource constraints, ethnical concerns and personal and collective values. Dialogue seeks to convene the diversity of community stakeholders, mitigate power dynamics in those relationships and facilitate deep trust to better understand complex social problems, while identifying and leveraging existing capacity to find potential solutions for those problems.

BRCAinBC is a community-based initiative and we have often used community dialogue as the mechanism to identify and engage stakeholders on BRCA-related issues for people of Ashkenazi Jewish descent. The goal of these dialogues is to build knowledge, understanding and enable solutions to emerge. Important stakeholders for dialogue thus far identified in the area include:

- individuals and families personally affected by the BRCA genes in BC;
- the broader community of Jewish people at elevated risk for BRCA-related cancers including religious and other community leaders;
- activists in the BRCA and cancer communities, academic researchers in the area of genetics, men's and women's health;
- medical specialists in the area of hereditary cancers (including genetic counselors);
- primary care practitioners (including NPs);
- healthcare administrators; government officials;
- charitable and non-profit organizations working the area of hereditary cancers, men's and women's cancers and cancer care, private community donors with an interest in BRCA, fertility specialists and other allied health professionals, including those who provide paramedical services to people who have undergone prophylactic surgeries.

Through our continuing engaged dialogues with these various stakeholders, we have identified gaps in care in British Columbia, at-risk stakeholder subgroups of concern, both predominant and underserved, areas of opportunity for action and growth, and existing and potential resources to support addressing those concerns. Our goal through this process is not to become the sole provider of solutions for the community in this area, but to support our community and broader system to better understand the issues and engage in action that will ultimately address them. For more literature on dialogue and its value in systems change, please refer to Daniel Yankelovich's (1999) "The Magic of Dialogue."

Current/Active Committee Members:

Jane Remocker – Chair, Community Member

Beti Thompson – Co-Chair, Professor Emeritus, Cancer Prevention Program, Fred Hutchison Cancer Center

Rabbi Infeld, Head Rabbi, Congregation Beth Israel

Catriona Remocker, MPH – Knowledge Mobilization Manager, Systems View Psychotherapy

Dr. Rona Cheifetz, Medical Lead, Hereditary Cancer Program High Risk Clinic, BC Cancer

Dr. Lesa Dawson, Gynecologic Cancer Prevention and Survivorship Clinic, VCH and Gynecologic Cancer Initiative, UBC

Lara McLachlan, M.Ed, Community Member (Secretary)

Allison Mindlin, Genetic Counsellor, Hereditary Cancer Program, BC Cancer

Hilary Vallance, Investigator and BC Children's Hospital Director, Provincial Newborn Screening Program

Dr. Irving Rootman, Health Promotion Specialist, Adjunct Professor, University of Victoria

Tovah Carr, Community Member

Lee Simpson, Community Member

Ginaya Peters, Community Member

Shaeri Gaerber, Community Member

Carly Pistawka, Genetic Counselling Student, UBC

BRCAinBC 2018 - 2022: Summary of Achievements

General Accomplishments since 2018

- Created a multidisciplinary committee of healthcare professionals, patients and family members interested and actively supporting the work of BRCAinBC
- Created active and engaged relationships with BC Cancer's Hereditary Cancer Program High-Risk Clinic, Beth Israel Synagogue, Vancouver Talmud Torah's PAC committee, Jewish Federation of Greater Vancouver, the Jewish Community Centre of Greater Vancouver, UBC's Gynecological Cancer Initiative, Temple Sholom's Men's Group, Olive Fertility, Diamond Foundation, and the Znaimer Family Foundation
- Created a part-time Knowledge Mobilization (KM) Support Manager position to support the work of the community in a sustainable and ongoing way
- Provided support and input on several current and completed research projects across Canada

Pillar 1a: Community Education (BC Jewish community)

- Launched BRCAinBC website (2020), which was made in collaboration with BC Cancer and is endorsed and supported by local health officials: www.brcainbc.ca
- Held 1 large-scale general in-person Vancouver community education event (200+ attendees) (January 2020)
- Held several virtual community education webinars (engaging general BC Jewish community, men x2, parents, BRCA carriers, and seniors (scheduled fall 2022)) (60+ attendees per event)
- Published articles in Jewish Independent (Catriona, February 21, 2020 <https://www.jewishindependent.ca/tag/remocker/> & Tovah, April 8 2022 <https://www.jewishindependent.ca/byline/tovah-carr/>)
- Created active Facebook and LinkedIn pages and engage with other important social media pages (e.g., BRCA Sisterhood Canada)
- Held Dinner & Dialogue event with Jewish young adults (social meal followed by discussion on health and genetic testing, 40+ attendees) (May 2022)
- Submitted Michael Smith Foundation grant application to support the development of a Community-Base Participatory Action Research project (CPAR) focused on producing digital media (videos on TikTok) to share information on the BRCA genes with youth and young adults in BC

Pillar 1b: Community Education (Healthcare Professional community)

- Held 1 accredited one-hour Specialist-targeted continuing education webinar (100+ attendees) (Rona and Lesa, September 2021) https://media.phsa.ca/home/iframe?url=BCCA/bccahealth%5cFPON_Sept_16_Webinar_Sept_16_20210916
- Held 1 Nurse Practitioner-targeted webinar in 2022 in collaboration with Nurses & Nurse Practitioners of BC (NNPBC, 40-50 participants) (Marco Gnoato)

- Created a physician education letter for patients to bring to GP appointments <https://www.brcaibc.ca/wp-content/uploads/2022/11/BRCAinBC-Letter-for-Physicians85.pdf>
- Article published by Allison and Rona in Journal of Family Practice Oncology (Issue 35, Fall 2020) http://www.bccancer.bc.ca/family-oncology-network-site/Documents/2020FallFPONjournal_Sep14web.pdf
- Article published by Lesa and Rona in Journal of Family Practice Oncology (Issue 38, Spring 2022) <http://www.bccancer.bc.ca/family-oncology-network-site/Documents/2022%20Spring%20FPONjournal%20WebMay5.pdf>
- Research seminar related to breast cancer with local, national and international contributors in November 2022

Pillar 2: Political Advocacy and Improving Access to Genetic Testing

- Created a genetic testing bursary for community members who do not qualify for testing through Hereditary Cancer Program (HCP)
- Created webpages outlining and detailing options for free and paid genetic testing options here in BC <https://www.brcaibc.ca/free-public-testing-options-in-bc/> and <https://www.brcaibc.ca/private-testing-options/>
- Met with a wide variety of interested stakeholder groups and researchers, locally, nationally and internationally to discuss the problem
- Gathered research to create and support a position with regard to population testing access of AJ community here in BC (limited bibliography attached)
- Submitted letters to key government officials regarding the issue
- Created conversations with key stakeholders (Jewish community, Diamond Foundation, BC Cancer, etc.) to elevate awareness of the need for improved access to genetic testing for the AJ community in BC
- From these conversations a recent \$100K grant was provided to BC Cancer's Hereditary Cancer Program to clear out genetic testing backlog and create a pilot study for population screening for AJ people here in BC

Pillar 3: Supports for BRCA+ Community Members

- Created webpages including information on BRCA-aware counsellors and support groups available, BC Cancers high risk and survivorship clinics (425 independent visitors monthly) and preventative options for individuals <https://www.brcaibc.ca/brca-support-groups/> <https://www.brcaibc.ca/bc-cancer-high-risk-clinic/> <https://www.brcaibc.ca/gynecologic-oncology-survivorship-clinic/> <https://www.brcaibc.ca/screening-prevention-for-women/> <https://www.brcaibc.ca/screening-prevention-for-men/>
- Held our first webinar for BRCA+ community members in BC
- Gathered and share stories of BRCA in our community for our website and webinars
- Laid the foundation for the creation of a virtual support group for BRCA+ people in BC (mandate create, structure created, partial staffing completed, marketing strategy completed, initial waitlist created)

Pillar 4: Fundraising

- 2019: \$12,477.00 from individual donors prior to 2020 community event
- 2020: \$5000 gift from Znaimer Family Foundation
- \$5000: annual grants from the Diamond Foundation: 2020,2021, 2022, and 2023 (confirmed recipient)
- \$4000: grant from the Diamond Family Foundation for Dinner & Dialogue 2022
- 2022: \$6000 gift Remocker Family
- 2020 - 2022: \$1500 unsolicited donations
- 2022: \$15,000 Reach grant from Michael Smith Health Research Foundation
- 2022: \$1450 PRE grant from UBC Community Engagement
- 2023: \$25000 Matching grant from Diamond Foundation for development of virtual support group

BRCAinBC 2022 - 2024: Moving Forward

General Goals

- Determine new committee home base: currently in progress with the Jewish Federation in Vancouver
- Incorporate as a non-profit: currently underway - documents submitted to Federation CFO
- Establish a sustainable core funding model for BRCAinBC
- Refine program model and service model of BRCAinBC with Hereditary Cancer Program High Risk Clinic

Patient, Family & Public Engagement

- Revamp BRCAinBC website, rebrand, currently in progress, to be completed in February 2023
- Deliver webinar for seniors focused on awareness-building (completed November 2022)
- Complete Dinner & Dialogue sessions (1 completed, 3 in progress)
- Develop sharable social media product for young people (In progress)
- Hire company to manage social media accounts for us (In progress)
- 2-3 more Dinner & Dialogue programs with focus on reaching unaffiliated Jews (In progress)

Health Professional Engagement

- Develop accredited family physician-targeted continuing education e-learning modules on hereditary cancer and premature menopause
- Hold 2nd Summit in hybrid format to exchange knowledge on hereditary cancer with current and potential partners
- Ongoing education for nurse practitioners in the province
- Approaching BRCA symposium about virtual involvement of an audience here in BC
- Approach prostate cancer field to co-author another article about the changes in NCCN testing guidelines
- Consider Mail Out thru Doctors in BC/post in chat

- Further explore potential support for education endeavors offered by the BC Cancer Foundation

Advocacy

- Develop an advocacy strategy identifying core issues, messages and stakeholders to engage
- Replicate Dr. R Manchanda's cost effectiveness study
- Explore successful Group Patient Advocacy ideas e.g., Hip Hip Hooray
- Connect with Canadian Cancer Society, InspireHealth and Ovarian Cancer Canada to explore opportunities for collaboration
- Evaluate improvement in community awareness of BRCA mutations
- Evaluate outcomes of our work to date
 - Get numbers of AJ's coming in to the Hereditary Cancer Program – pre-2020 vs. post-2020 getting tested for BRCA
 - Look at people who said no to AJ ancestry and people who said yes and look at relative comparison over time
- Advocate for mammography screening for at risk individuals
- Advocating for better education and options for surgical options for women who test positive
- Connect on the Provincial Young Adult Cancer Strategy with BC Children's to explore ideas for potential collaboration
- Annual chart review of wait times for surgery for HRC patients
- Embed a question in the HRC survey – e.g. "Once you wanted a preventative mastectomy, how long were you wait-listed for initial consultation until surgery?"
- Advocating for more OR time for reconstructive surgeons? one or two specialist reconstructive surgeons in the province whose only job is preventative mastectomy reconstruction and who are only seeing preventative cases?
- Advocating for mandatory notification of family members
- Complete and wrap up ongoing research projects

Supports

- Create virtual support group for BRCA+ carriers in the province (fundraising + hiring of facilitator, create a list of volunteers willing to develop topical presentations for each session): CUES grant submitted Jan 2023 plus potential matching support from Diamond Foundation
- Host fertility concerns webinar for BRCA+ individuals: scheduled for May 2023 with Olive Fertility

Fundraising

- Applied for \$25,000 UBC CUES Grant in partnership with BC Cancer to fundraise for BRCA+ support group (currently underway) Potential matching funds verbally committed Diamond Foundation
- Raised funds for social media program through a \$15, 000 Michael Smith Foundation grant
- Seek sustainable funding source for Knowledge Mobilization (KM) team annual support
- Consider approaches to Ovarian and Breast Cancer Foundations to fund community activities.

