

# Health Coalition of Alberta Society Annual Report 2017



# About the Health Coalition of Alberta Society

The Health Coalition of Alberta started in 2006 as an alliance of over 60 health charities, non-profit organizations and individuals with common health issues and concerns. This alliance became Creating Synergy Health Coalition of Alberta in 2008 and established its vision, mission, goals and strategic plan, which were supported in the transition to our current Society in June 2014.

The Health Coalition has more than 80 voluntary health sector organizations, consumer groups and individuals committed to working together and advocating with a united voice for better access to optimal health care for all Albertans. A voluntary board is elected by the membership and governs the Society

Primary initiatives of the Health Coalition include advocacy on key health care access issues, education of members and the public, and awareness regarding health care reform decisions and service changes which could impact Albertans, and particularly patients in their care pathways and health outcomes. We envision a health care system which is available with equal and equitable access by all Albertans regardless of condition or disability, age, income status and geographic location. We also want a system that is universal, people-centered, evaluated as being effective and efficient, timely and transparent. More information about the Health Coalition and our efforts can be found at <a href="https://www.healthcoalitionab.ca">www.healthcoalitionab.ca</a>.

#### **Our MANDATE**

The mandate of the Health Coalition of Alberta Society is to advocate for people-centered health care in Alberta. Through the strength of our membership we will be consulted with, and listened to, when decisions are made that impact the health of Albertans.

#### **Our PRINCIPLES** - Values We Collectively Share:

- A. Commitment to the public good and public benefit
- B. Integrity and Honesty
- C. Respect for all stakeholders
- D. Commitment to accountability and good governance
- E. Dedication to the pursuit of quality health care

Through ongoing engagement of our membership in activities that align with our mandate and principles the Health Coalition of Alberta Society is able to bring the voice of patients and their caregivers to represent our positions on common health and health care issues.

Together we will achieve our vision of the *best people-centered health care for all Albertans*.

Working together with you... for the best people-centered health care for all Albertans



# **2017 Board of Directors**

### President Bruce West



Bruce West is a continuing care advocate. He retired in October 2013 after five years as Executive Director of the Alberta Continuing Care Association (ACCA), a voluntary, non- profit advocacy organization that represents the owners and operators of long term care and supportive living facilities, and the providers of home care and home support services throughout Alberta. Prior to his time with the ACCA Bruce had a 30-year career with the Government of Alberta where he held a number of senior management positions related to Alberta's housing and continuing care systems. Bruce has particular interests in promoting high quality and sustainable seniors housing, health care and continuing care to enhance the quality of life of Albertans.

#### Treasurer Mary Chibuk



Mary has been a long time health care advocate, both on a personal and professional level, working with children with disabilities, in cardiac care, persons with Parkinson's, and cancer care. Experienced in nonprofit management she has served on numerous Boards and been an Executive Director and has been a member of the Health Coalition of Alberta (Creating Synergy) as a volunteer since the beginning. As a long-time member of Girl Guides of Canada she also serves as the Alberta provincial fund development grants coordinator.

#### Nomination Committee Chair Tom Perkins



My name is Tom Perkins, B.Ed. I taught Special Education students for 27 years. I am one of the original directors of the Alberta Porphyria Society, now the Canadian Association for Porphyria.



## Member-at-Large Angeline Webb



Angeline Webb is Regional Manager with the Canadian Cancer Society, Prairies, where she has been engaged in health policy advocacy and health promotion for the last 14 years. She develops, implements, and administers public health advocacy, health policy development programming and health promotion programming for the Canadian Cancer Society in the Prairie and Northern regions as well as at the federal level. Angeline's focus is healthy public policy and chronic disease prevention with most of her attention devoted to tobacco reduction policy development.

### Member-at-Large Fraser Hall



Fraser Hall is a Services Specialist a for Muscular Dystrophy Canada. In that role he supports individuals and their families who are affected by neuromuscular disorders, by helping navigate health care systems, community supports, recreation opportunities and financial aid. He also advocates for patient rights, caregiver supports and accessibility issues. He also has a background working with individuals with special needs and outdoor Education.

#### Member-at-Large Teren Clarke



Teren is the CEO with Spinal Cord Injury Alberta and Executive Director of the Alberta Paraplegic Foundation. She has been in this role since 2005. Prior to that, she worked with Muscular Dystrophy Canada between 1993 and 2005 in roles including National Director of Programs, Prairies Executive Director and Provincial Services Director. Teren was appointed by the Federal Minister of Health to the inaugural Stem Cell Oversight committee and served for four years. She also served on the Advisory Committee for the Institute of Genetics, one of the Canadian Institutes of Health Research for four years. Teren earned a BN from the U of C and a Masters in Management from McGill University.



#### Member-at-Large Joan King



Joan King is the Government Relations and Advocacy Lead for Diabetes Canada in Western Canada. Joan has been a passionate diabetes advocate for over 19 years, working with Diabetes Canada's National Advocacy Council and hundreds of volunteers in advocating the positions and policies of Diabetes Canada to the Canadian public, governments, non-government organizations and the media on behalf of the diabetes community in Canada. Following the completion of her Business and Commerce degrees, she worked at the Youth Emergency Shelter Society in Edmonton.

## Executive Director Beth Kidd



Beth has 25 years of experience in developing, directing, and implementing patient advocacy, government relations, public relations, and marketing strategies. Beth has spent the majority of her career in the health charity sector although she came to the Health Coalition of Alberta from the corporate world. Beth is a lifelong volunteer with many charities, political parties and community groups. She is a member of Migraine Canada's newly formed Board of Directors. In the past, she helped to establish the Creating Synergy Health Coalition, served on the Steering Committee for the Alberta Disabilities Forum as well as the advocacy committee for the Calgary Chamber of Voluntary Organizations.



## **PRESIDENT'S REPORT**

I am pleased to present the Health Coalition of Alberta's annual report for 2017. There have been a number of changes as we approach the mid-term point of our Strategic Plan for 2016-2020. What has not changed, however, is the Board of Director's commitment to advocate for people-centered health care in Alberta. I want to thank all of our members for their support of this mandate and welcome new members to the Coalition. We are very happy to report an 18 per cent growth in membership in 2017!

Two Directors who were elected to the Board at the 2016 AGM tendered their resignations in 2017. Kathy Watson resigned in September and Kathy Kovacs Burns resigned in December. Both are still members of the Coalition but, like many of us, found it increasingly difficult to manage time commitments for work, family and their role as a Health Coalition volunteer. On behalf of the Board of Directors and staff at the Health Coalition of Alberta, I want to thank both of these individuals for their volunteer service and dedication to patient advocacy in Alberta. I would especially like to recognize Kathy Kovacs Burns' tireless leadership efforts on behalf of the Coalition since its inception.

The Board has heard a very clear message from our members that it is a challenging time to be a health charity in Alberta. The economic downturn has impacted all of us and many have changed their services and function in order to thrive in this environment. One project our Board undertook in 2017 was to review our bylaws and ensure they still meet the needs of our members and allow the Coalition to operate effectively. As a result, we have produced a Special Resolution package to update our bylaws at the AGM. I look forward to hearing your comments on these proposed revisions.

The Board of Directors also worked with Beth Kidd, our Executive Director, to find ways to diversify our funding base. Because our primary purpose is advocacy, we are unable to become a charity and that hinders our ability to fundraise. For example, we are greatly restricted in applying for many grants, bursaries and other sources of funding simply because we are not a charity. We were unsuccessful in securing a Community Investments Program (CIP) grant in 2017 because our Coalition primarily serves other organizations and not individuals. We will continue to search for ways to diversify our funding in 2018 but that may be a focus on expanding our corporate supporter base. As such, we have developed and launched a Corporate Supporter program in 2018 that ensures transparency and consistency for our contributors.

I am proud of the work achieved by both Board and staff in 2017. We are excited about the work underway for 2018 and look forward to improving the effectiveness of the Board's governance role while providing assistance to achieve operations excellence. In March 2018 the Board participated in a two day Board Development Workshop sponsored by Alberta Culture and Tourism.



I would like to thank our paid members, donors and gift-in-kind supporters for their ongoing contributions that drive the Coalition's work. Nothing could be achieved without the collaboration of our members and supporters. I also want to thank our volunteer Board of Directors for contributing their time and providing guidance and advice to shape our future.

In closing, I want to encourage you to provide us with your insight and expertise. Your feedback ensures the Health Coalition of Alberta is able to bring the voice of patients and their caregivers to represent our positions on common health and health care issues. With a provincial election on the horizon, now is a key time to coordinate and focus our advocacy efforts.

#### **Respectfully submitted**

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Bruce West President



## **EXECUTIVE DIRECTOR'S REPORT**

2017 proved to be a year of change, growth and action for the Health Coalition of Alberta thanks to the support from our members, supporters and Board of Directors. It was the second year of our five year strategic plan. Its focus on rejuvenating the Coalition and ensuring we continue to thrive well into the future is proving effective. Here are some key facts:

- paid membership increased by 18%
- financial contributions increased by 25%
- participation at our members' event grew by nearly 10-fold
- social media presence via Twitter grew by 50%

I'd like to thank Pfizer Canada, Novartis Canada, AstraZeneca Canada and Alberta Innovates for their financial contributions in 2017. Support from partners like these ensures the Health Coalition is able to focus on achieving our strategic plan and our mission to advocate with a united voice for better access to optimal health care for all Albertans.

To ensure the Coalition reflects the views of our members, we conducted an extensive outreach campaign in 2017. We distributed several surveys as part of monthly updates to members as well as met with members in person, by phone and email. As a result, we updated our advocacy priorities, our communication methods and our action plan. We heard that our members want the Coalition to take a proactive role in driving patient advocacy and shaping health policy. Due to the current economic environment in Alberta, many members no longer have the resources for this role and want the Health Coalition to move from education and empowerment to action. Member feedback also revised our advocacy priorities to: Improving access to care for all Albertans; Improving Access to Pharmaceuticals for all Albertans; and, Incorporating Patient Engagement and Partnership in Health care Discussions/Decisions.

I appreciate those members who share their stories about advocacy issues with me. I had a poignant conversation with a young woman who demonstrates why our access to medications priority is so vital. She told me she was taking an approved and funded medication for her retinal eye disease. After the RAPID program was launched, she was switched to an unapproved medication that is funded through the Alberta Health program. Sadly, after the switch she experienced two eye hemorrhages and could not see. She endured difficult medical appointments as she pleaded to be switched back to her funded and approved medication. Finally, her only option was to switch specialists. Thankfully, her eye health is recovering and she realized the importance of sharing her story. I am now telling it during our MLA and government meetings as it demonstrates the importance of patient participation when governments develop policies that impact care.



Other 2017 deliverables include:

- Created a submission to the Alberta government for the Fair and Family Friendly Workplaces Act; all recommendations were incorporated.
- Collected member feedback to help shape two national surveys on evaluating the health care system and access to medications issues.
- Gathered member feedback and research to produce a policy paper and position statement on access to biologics and biosimilars to ensure optimal care for patients. Communicated this position to government and key stakeholders.
- Conducted an MLA outreach campaign to drive education about the Coalition, the work our members do, and, two key priority areas: access to care; and, access to medications. We met with six targeted MLAs including the Minister of Health, Associate Minister of Health and the Minister of Seniors.
- Used member feedback to develop a position on national pharmacare.
- Educated Board of Directors and members about the impact of potential Patented Medicine Prices Review Board (PMPRB) changes.
- Connected with key stakeholders: Bio AB, Innovative Medicines Canada, Dementia Network Calgary, Best Medicines Coalition, University of Calgary, Alberta Alliance on Mental Health, etc.

The Board of Directors has approved a robust tactical plan for 2018 that includes:

- Continue our MLA outreach to ensure we meet with all parties.
- Meet with Alberta Health staff to about our advocacy priorities and achieve outcomes for our three asks: secure position on biologics/biosimilars committee; develop a process for patient feedback on medication funding decisions; work with AB Health to find solutions to care gaps.
- Meet with Alberta Health to discuss RAPID program outcomes and encourage patient partnership and choice.
- Develop and begin delivery of a provincial election advocacy plan.
- Launch a series of webinars with potential topics to include: biologics/biosimilars in AB; medical cannabis; personalize medicine developments; advocacy training.
- Rebuild and launch the Coalition's website.

I'd like to thank all our members and supporters for your guidance and support. I received such a positive reception from everyone I communicated with in 2017! It confirmed my belief in the need for the Coalition and our work. Thank you to those members who participated in our MLA outreach campaign. I hope you found value in the meetings. Please reach out to me if you want to become actively involved in our work. I appreciate the volunteer support!

Respectfully submitted,

R. Kidd.

Beth Kidd Executive Director



I am pleased to present the Health Coalition Treasurer's Report for the 2017 fiscal year.

Financial statements for 2017 will be shared with members at the AGM.

Mary Chibuk, MSc Treasurer & Board Director