

Annual Report 2023





WHOWEARE

The Health Coalition of Alberta is an alliance of health charities, patient groups, non-profit organizations, and individuals driven by a unified purpose. Through the strength of our membership, we have voice and influence into public health decisions that impact the health of Albertans.

Formed by a group of volunteers in 2006, the Health Coalition of Alberta formalized as a registered non-profit society in 2014. Our membership base quickly grew to one of the largest advocacy coalitions of this kind in Canada; more than 100 members inform our work.

We use a collaborative, solution-focused approach to engage with governments, health policy decision-makers and other stakeholders to achieve our goals.

We recognize that, for many reasons, not all users of the health care system choose to be referred to as patients. However, we use this collective term to positively reinforce the concept that the health care system must be effective for each person in care regardless of the services they receive or where they are served. It also differentiates the unique voice of people with lived experience from health care providers and other professionals.

The Health Coalition of Alberta purpose is to advocate for the adoption of a relational model of care that is centered on patient needs to achieve their full health potential. We support shared decision-making between the health care team and educated and informed patients in order to make choices that will have the most impact on not only the health but also the emotional and social needs of each individual.

We achieve our purpose by: advocating on key health care issues; educating our members and the public so they can engage effectively with the health care system; and, by raising awareness and stimulating dialogue around health care policy and service changes that impact Albertans.

Our VISION:

We envision a health care system where all Albertans have an equitable voice and access to services needed to achieve their full health potential.



PRESIDENT'S REPORT

As we reflect on the year 2023, the Health Coalition of Alberta (HCA) has continued to advance our vision of a healthcare system where all Albertans have an equitable voice and access to services needed to achieve their full health potential.

One of our key accomplishments was launching the Board Mentorship Program, which stabilized Board membership and facilitated nominees making informed decisions to join. In 2023, we welcomed three new members and are excited to bring forward four more names this year.

Our membership proactively grew another 10% as we reached 117 members in 2023, indicating our increasing relevance and impact. Seventy-four members represent organizations, from within Alberta and across Canada, showcasing our broad support base.

The Health Coalition of Alberta is also beginning to build a volunteer base beyond our Board of Directors. I extend a welcome and heartfelt thanks for your time: Katie Kidd, Jillian Kidd, Catriona Berry, Anne Babineau, Candice Laws, Lori Williams, Dave Cournoyer, Joe Farago, and Mat Steppan.

I also want to extend a special thank you to our dedicated Board of Directors for volunteering their time, expertise, and leadership. Your commitment is instrumental in guiding HCA's strategic direction and ensuring our initiatives are effective and impactful.

Sadly, in 2023 we mourned the loss of Dr. John Bachynsky, a long-standing member and former co-Chair. His advocacy for health policy and seniors' issues, as well as his role in connecting HCA with the University of Alberta Faculty of Pharmacy, leaves a lasting legacy. We continue to educate future healthcare pharmacy leaders through lectures on patient advocacy in his honor.

In 2024, HCA remains committed to our vision. We will advocate tirelessly, engage stakeholders, and strengthen partnerships to drive meaningful change. Thank you for your support and dedication.

Respectfully submitted

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Scott McRae President



EXECUTIVE DIRECTOR'S REPORT

2023 proved to be an eventful year in Alberta, marked by an intense election campaign that captured widespread attention across the province. Amidst this backdrop, the Health Coalition of Alberta (HCA) remained steadfast in our commitment to advocating for meaningful health care reform and advancing a relational model of care. We have made significant strides in advocating for our strategic priorities. As we embark on 2024, I am delighted to share a summary of our achievements over the past year.

Throughout 2023, the Health Coalition of Alberta actively engaged in strategic meetings and consultations with provincial and federal governments, as well as key stakeholders. Our efforts were guided by our 2022-25 Strategic Plan, focusing on priorities such as health equity, patient engagement, relational care, and improved access to medications and devices. You can find specific details showcased under Operational Highlights in this annual report.

As is evident in this summary of achievements and activity, the Health Coalition of Alberta witnessed a significant shift in patient engagement. I applaud all our members who continually ask the question: Did patients co-design this approach? Working together we will achieve widespread acceptance of patient expertise!

The fundamental approaches outlined in our Patient Engagement Guide are being more widely adopted, not only by governments, political parties and health decisions makers but also by the pharmaceutical industry. We experienced a concerted move towards incorporating patients as co-developers with medications being launched in Canada. In 2023, the HCA participated in a notable example of patient partnership. Eisai Limited collaborated with health charities, patients, caregivers, advocates, primary care networks, and industry stakeholders to enhance the diagnosis and care pathway for people with mild Alzheimer's Disease (AD). This collaborative effort focused on co-learning and a people-first approach, uncovering a diagnosis disparity that they are now working to address together with those affected by dementia, fostering hope and collective action.

On a more personal note, I want to pay tribute to Dr. John Bachynsky, who sadly passed away in November 2023. As you will read in our President's Report, John was a long-standing leader at the Health Coalition of Alberta. I had known John for more than 20 years and considered him a mentor. I greatly admired his willingness to speak up on issues as well as his boldness in pointing out gaps and consequences related to policy and health care decisions. He was a champion for patient engagement and a role model for many advocates.



I extend my sincere gratitude to our Board of Directors and our dedicated team of volunteers whose time and expertise are essential in fulfilling our purpose at the Health Coalition of Alberta. I also want to express appreciation to my colleague, Jaymee Maaghop, for her unwavering support and commitment to our collective endeavors at HCA. Our efforts in 2023 have not only enhanced our advocacy capabilities but also positioned the HCA as a key influencer in shaping health care policies that prioritize patient needs. We have effectively supported our members, shaped government policies, and contributed to meaningful discussions on health care reform.

As we move forward into 2024, the Health Coalition of Alberta remains committed to advancing our strategic priorities and advocating for a health care system that ensures equitable access and a relational model of care. We will continue to engage with stakeholders, collaborate with government partners, and support our members in navigating the evolving health care landscape.

Thank you for your unwavering support and engagement throughout the year. Together, we will continue to make a positive impact on health care in Alberta.

Respectfully submitted,

B. Kidd.

Beth Kidd Executive Director

Our ACTIONS:

- Advocate on key health care issues.
- Educate our members and the public so they can engage effectively with the health care system.
- Drive awareness and dialogue about policy and service changes impacting Albertans.



OPERATIONAL HIGHLIGHTS

Political Engagement:

Organized a robust election campaign, featuring multiple member webinars and a meet-thecandidates session. A campaign kit equipped our members with essential tools, ensuring informed participation. Post-election, we introduced the HCA to new MLAs and ministerial portfolios. Government discussions in 2023 primarily focused on the Minister of Health, Minster of Mental Health and Addictions and the Minister of Seniors, Community and Social Services as well as Deputy Ministers and Assistant Deputy Ministers and other senior staff. We also had briefings with many key opposition MLAs like David Sheperd, critic for primary and rural care and, Luane Metz, critic for emergency and surgical care health issues. We provided feedback at every opportunity through surveys, distributing a budget submission and attending events.

Health care Reform:

Monitored regulatory developments closely, participated in government briefings and webinars to relay updates to members. Engaged in extensive government consultations, including sessions on the Continuing Care Act and the modernization of Alberta's primary care system. We provided substantive input aimed at enhancing care delivery and patient outcomes while focused on a relational model of care.

Additional Advocacy:

Monitored and responded to developments on topics such as National Pharmacare, PMPRB, pCPA, the National Rare Disease Strategy, the Alberta drug plan, Medical Assistance in Dying, etc. Our submissions and feedback emphasized the importance of patient engagement and advocated for policies that prioritize patient needs.

Research, Insights and Policy Development:

Provided critical insights through our research initiatives on return to care, health care reform, and oncology care in Alberta. These findings informed our advocacy positions and recommendations during consultations with government and external stakeholders. We also initiated research to establish best practices for virtual care from a patient perspective and continued to gather evidence to support our call to adopt a relational model of care by collecting patient stories. We assessed and developed positions to support the Truth and Reconciliation Commission of Canada: Calls to Action, embedding these recommendations across our communications. We completed our draft paper exploring Informed and Educated Consent. We investigated Alberta's electronic medical record systems, in comparison to other jurisdictions, patients' rights to their medical information and started to formulate positions on patient access to build content for a position paper.



Educational Initiatives:

Hosted four member webinars such as "*Demystifying Delays: How to Navigate Access to Medications*," providing practical guidance to members on navigating health care access challenges. We also updated our comprehensive Patient Engagement Guide to include new insights on equitable and balanced patient representation, health equity and marginalized communities, as well as compensation implications. We also created an infographic to enhance accessibility and impact. We delivered an education lecture focused on patient advocacy and health equity to more than 50 Faculty of Pharmacy students at the University of Alberta.

Member Services:

Strengthened member engagement through Monthly Coffee Catch Up sessions, detailed email updates featuring policy briefs, summaries of governmental mandates, and informative webinars. We provided tailored support, responded promptly to member inquiries, guidance on advocacy approaches and conducted advocacy trainings.

Patient Engagement Consultations:

Consultations included providing patient/caregiver feedback about: streamlining quicker access to medications via Health Canada, CADTH, and the pCPA; medication access timelines and awareness of Project Orbis; and, at the Institute for Health Economics' "Operationalizing Innovative Managed Entry Agreements in Canada: a national multi-stakeholder workshop." We brought caregiver and patient perspectives about access to care to the MRI Workshop consultation. HCA also participated in the Cardiovascular Disease and Health Policy interview series, the Cardiovascular Disease Canadian Stakeholder Policy and Advocacy Roundtable, the Dementia Care Partner Dialogue, and the National Obesity Advocacy Summit.

External Relations:

Actively participated in public events and forged partnerships to elevate the HCA's profile as a health care stakeholder. We attended events, responded to speaking engagement requests and contributed to consultations. This outreach included the Canadian Association of Health care Reimbursement, Bio Alberta, the CADTH Symposium, Research Canada's Parliamentary Caucus event and AGM, AB SPOR, Alberta's International Medical Graduates Association and many election and community events.



TREASURER'S REPORT

I am pleased to present the Health Coalition of Alberta Society's Financial Statements for the 2023 fiscal year.

In the statement of financial position, the Health Coalition of Alberta ended the year with a strong net asset position of \$148K which includes \$1.1K in computer equipment for virtual functionality and security for the Executive Director.

Revenues of \$130K were recognized in 2023, an increase of \$20K or 18% from the prior year, which includes \$120K in corporate sponsorship, \$3.5K in membership fees, \$3.3K in honorariums from speaking engagements and \$2.8K in interest income, all having increased due to the strong efforts by the Executive Director and the Administrative Assistant to continually maintain and strengthen our supporters and membership base.

Overall expenditures of \$113K for 2023, an increase of \$17K or 17% from the prior year, which primarily relates to an anticipated increase in contractor hours during the year. The Health Coalition of Alberta experienced an operating surplus of \$17K for 2023.

The Health Coalition of Alberta's financial statements for 2023 will be provided to all voting members and shared at the AGM.

Respectfully submitted,

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Karen Knutson Treasurer



2023 CORPORATE SUPPORTERS

Funding from our Corporate Supporters helps the Health Coalition of Alberta to focus on achieving our strategic plan and our mission. We thank all our Corporate Supporters for their commitment to ensuring patients are included in health care decisions.

GOLD:



INVENTING FOR LIFE

SILVER:

Janssen Inc. Innovative Medicines Canada Gilead Sciences Canada GSK Canada Novartis Pharmaceuticals Canada Inc.

BRONZE:

AbbVie Corporation Eisai Limited Incyte Biosciences Canada Corporation

GIFT IN KIND:

Microsoft Canada Canva



2023 BOARD OF DIRECTORS

President Scott McRae



Scott McRae works in the health charity sector after prior jobs as a writer and woodworker. Scott graduated from the University of British Columbia with a Bachelor of Arts in political science, and currently lives in Calgary

Vice President Joanne Wall



With a lifelong interest in health, Joanne completed post-secondary education and worked at the universities of Calgary and BC and other post-secondary institutions. She then moved to the private sector (pharmaceuticals) where she worked with health care professionals in many therapeutic areas. This work as well as being a caregiver to parents/friends with chronic illness resulted in an understanding of the needs of patients. She is motivated to find solutions (including health system navigation) that benefit the patients, their families, and the crucial health care teams.

Treasurer Karen Knutson



Karen is a Holistic Nutrition Coach, helping people overcome health and wellness issues and related chronic conditions. She is based in Calgary and is also a CPA – CA with a Masters in Professional Accounting. Karen has over 15 years of experience in corporate accounting, finance, and leadership roles. Karen previously worked with professionals to help them gain control over their personal and professional finances. She was also the Manager of External Reporting & Internal Controls for WestJet and has served as a director and treasurer on various not-for-profit boards.



Secretary Heather Templeton



Heather began her healthcare career in 2008 as a Licensed Practical Nurse in long-term care and hospice. She then received her master's in leadership and ministry. Prior to her career in nursing, she worked in seniors' lodges and her desire to work with seniors grew. She has also worked for the Alzheimer Society of Calgary in their Club 36 program.

Heather is currently the Advocate Training and Education Coordinator at Open Arms Patient Advocacy and is a presenter and member of the planning committee of Dying with Dignity Calgary. In all her roles, ensuring the resident or patient was treated with dignity and respect is extremely important.

Member-at-Large Tim Battle



Tim has worked extensively in the non-profit sector, in education and various leadership roles. He also has broad experience in governance, and currently sits on the board of directors for several organizations. Tim has been involved in several health advocacy initiatives and has a special interest in the areas of mental health and caregiver support. Tim has been an active member of the Health Coalition of Alberta since he joined in 2019.

Member-at-Large Shirley Duia



Shirley is a graduate student in neuroscience at the University of Alberta. Shirley has been passionate about health care from a very young age. Her mother is a family physician and a role model for Shirley. Her ambition is to enter medical school and become a doctor. Shirley is a volunteer ER attendant at the Misericordia Hospital where she aids nurses and provides assistance to patients and visitors. She also volunteers at Villa Caritas and provides support to seniors. Her volunteer experience includes special events like the Heritage Festival and Walk for Seniors as well as helping at the Mustard Seed kitchen. Shirley's goal is to learn about other aspects of health care, including how to enable easily accessible health care for all.



Member-at-Large Jeff MacKay



Jeff has been a patient his whole life and has the scars to prove it. In the process, he learned the importance and necessity of patient advocacy and experienced just how effective patient focused healthcare can be.

A transplanted bagpiper from the east coast, Jeff takes his triplets to the hike and play in the mountains every chance he gets. Professionally, Jeff enables team-based and patient inclusive care with technology and privacy compliance support as the Director of Marketing at Brightsquid Secure Communications Corp. Working with providers, administrators, and patients throughout Alberta and beyond has given Jeff a unique understanding of the challenges faced by everyone involved.

The way the Health Coalition of Alberta represents a unified voice for common patient interest across a wide spectrum of experience and need is a cause Jeff believes can inspire improved care for all Albertans in the near-term and for generations to come. Jeff has been a member of the Health Coalition of Alberta since 2018.

Past President Teren Clarke



In June 2023 Teren joined the board of Spinal Cord Injury Alberta and became a member of the executive committee. She is the former Chief Executive Officer with Spinal Cord Injury Alberta and Executive Director of the Alberta Paraplegic Foundation until Sept 2019. In retirement she served as a patient and family advisor for the Strategic Clinical Network (SCN) for Neurology, Rehabilitation and Vision, an initiative of the Alberta Health Services. The SCN was disbanded by AHS in May 2024. She was an active participant in several working groups with the SCN. Teren was with SCI Alberta from 2005 to 2019. 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 earned a Bachelor of Nursing from the University of Calgary and a Masters in Management from McGill University.



Ex Officio Director Fraser Hall



Fraser Hall has been a Services Specialist for Muscular Dystrophy Canada and is now in a fund devolvement role with MDC. In these roles, he works with various stakeholders who are affected by neuromuscular disorders, by helping navigate health care systems, community support, recreation opportunities, financial aid as well as sharing the impact the organization does with perspective doners. He also advocates for patient rights, caregiver support, and accessibility issues. He also has a background working with individuals with special needs and outdoor Education.

Ex Officio Director Joan King



Joan King is a Government Relations and Advocacy Director for Diabetes Canada. Joan has been a long-time patient advocate working for Diabetes Canada and with health coalitions and partner health charities. Joan has worked with hundreds of volunteers in advocating the positions and policies of Diabetes Canada to the Canadian public, governments, nongovernment organizations and the media on behalf of the diabetes community in Canada.



2023 STAFF

Executive Director Beth Kidd



Beth has more than 25 years of experience in developing, directing, and implementing patient advocacy, government relations, public relations, and marketing strategies. Beth has spent most of her career in the health charity sector although she came to the Health Coalition of Alberta from the corporate world. Beth is a life-long volunteer with many charities, political parties, and community groups. Currently, she volunteers with Research Canada's Board of Directors, CADTH's Patient and Community Advisory Committee, and Dementia Network

Calgary's Strategic Council. A patient advocate herself, she is also one of the leaders with Migraine Warriors Alberta and a caregiver to her loved ones.

Administrative Assistant Jaymee Maaghop



Jaymee provides organizational support to the Board, the Executive Director, and the Coalition members on a part-time basis. Jaymee has been working with patient organizations from various therapeutic areas on health care policy and access issues. While she is based in BC and works full-time for a member organization, the Gastrointestinal Society, she is proud to support the Health Coalition of Alberta in achieving its mission for better access to optimal

health care for all Albertans.

Our GOALS

- 1. Foster a strong coalition.
- 2. Deliver member & public education.
- 3. Champion health equity.
- 4. Amplify patient & caregiver voice.
- 5. Promote a relational model of care.
- Improve access to medications & medical devices.



OUR MEMBERS

Alberta Community Council on HIV Alberta Continuing Care Association Alberta Council on Aging (ACA) Alberta Hospice Palliative Care Association Alberta Pituitary Patient Society Alberta Seniors & Community Housing Association ALS Society of Alberta Alzheimer Society of Calgary Alzheimer Society, Alberta and Northwest Territories Aplastic Anemia and Myelodysplasia Association of Canada/Network of Rare Blood Disorders Arthritis Society Canada Autism Society of Edmonton Area Brain Care Centre Canadian Association for Porphyria Canadian Association of Pompe Canadian Association of Psoriasis Patients **Canadian Cancer Society** Canadian Cancer Survivor Network Canadian Coalition of Global Health **Research Alberta Chapter Canadian Liver Foundation** Canadian Mental Health Association, Edmonton Region Canadian Mental Health Association, Alberta Division Canadian MPN Research Foundation Canadian Psoriasis Network **Canadian Pulmonary Fibrosis Foundation Canadian Pulmonary Hypertension** Association of Canada Canadian Spondyloarthritis Association Canadian Down Syndrome Society **Caregivers** Alberta **CARP** Calgary Chapter **CARP Edmonton Chapter**

Cerebral Palsy Association in Alberta CNIB AB & NWT/ Vision Loss Rehab **Creekside Support Services Ltd** Crohn's and Colitis Canada Cystic Fibrosis Canada - Calgary & Southern AB Chapter Cystic Fibrosis Canada - Edmonton & Northern AB Chapter **Dementia Network Calgary Diabetes Canada** Easter Seals Alberta Edmonton Down Syndrome Society **Epilepsy Association of Calgary** Fibromyalgia Society of Edmonton and Area **Gastrointestinal Society - Canadian Society** of Intestinal Research Greg's Wings Heart & Stroke **HIV Network of Edmonton Society** Huntington Society of Canada, Southern Alberta Kidnev Foundation of Canada - Southern Alberta Branch Kidney Foundation of Canada - Northern Alberta & Territories Leukemia & Lymphoma Society of Canada Lung Association - Alberta and NWT Lupus Society of Alberta M.E. Society of Edmonton March of Dimes **Migraine Canada MS Society** Muscular Dystrophy Canada - Prairies & NWT My Everything Store Inc Myeloma Alberta Support Society Natural Health Practitioners Canada Oladele Foundation/African Cancer Support Group



Open Arms Patient Advocacy Society Osteoporosis Canada - Alberta Chapter Osteoporosis Canada - BC & Alberta Region Parkinson Association of Alberta Psychologists' Association of Alberta SafeLink Alberta Save Your Skin Foundation Schizophrenia Society of Alberta Southern Alberta Myeloma Patient Society SouthWest Edmonton Seniors Association (SWESA) Spina Bifida and Hydrocephalus Association of Northern Alberta Spinal Cord Injury Alberta **Turning Point Society** Unmasking the Reality of Lung Cancer Ups and Downs - Calgary Down Syndrome Association Voice of Albertans with Disabilities John Bachynsky Tim Battle Judy Birdsell **Rick Brick** Kathy Kovacs Burns Mary Chibuk Teren Clarke Shirley Duia **Beverley Dunn** Lynne Eikel

Salim Esmail Sandra Fiolka Darlene Gallant Fraser Hall Susan Hnetka Ravne Johnson Joan King Karen Knutson Linda Kolewaski **Corrine Kushneryk Rita Lyster** Jeff MacKay Austin Mardon Michelle Marusiak Darrel McKenzie Scott McRae Larry Pempeit **Tom Perkins** Mitchell Ravvin Marichelle Rogers **Catherine Ryan** Rhonda Shkrobot Katie Soles Dick Swaren Heather Templeton Joanne Wall Kathy Watson Bruce West Meaghan Wright

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