

LIST OF REGISTERED PATIENT GROUPS

Last updated January 12, 2018

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Patient Group Name	Who the organization represents	Website (if available)
A		
AboutFace Craniofacial Family Society	People living with facial differences both congenital birth defects, such as cleft lip and palate, hemangioma, apert, etc. or acquired facial disfigurements, such as burn, cancer, accident, etc. and their families.	www.aboutface.ca
aHUS Canada/SHUa Canada	Patients and caregivers and their families	www.ahuscanada.org
Aldergrove People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Alzheimer Society of BC	People living with Alzheimer’s disease and other related dementias and their families	www.alzheimerbc.org
Aplastic Anemia and Myelodysplasia Association of Canada	Persons with Aplastic Anemia, myelodysplasia and Paroxysmal Nocturnal Hemoglobinuria (PNH)	www.aamac.ca
Arthritis Consumer Experts	People living with arthritis	www.jointhealth.org
The Arthritis Society, BC & Yukon Division	People of all ages living with arthritis	www.arthritis.ca
ASIC (Access for Sight Impaired)	Blind and Partially-Sighted British Columbians	www.asicbc.ca
Asthma Society of Canada – National Asthma Patient Alliance	Patients with asthma and associated allergies across Canada	www.asthma.ca/napa

Patient Group Name	Who the organization represents	Website (if available)
B		
BC Association of Pregnancy Outreach Programs	Pregnancy outreach programs supporting marginalized and vulnerable women who are pregnant, post-partum or transitioning into parenting	www.bcapop.ca
BC Epilepsy Society	People affected by epilepsy	www.bcepilepsy.com
BC Healthy Living Alliance	Those with chronic disease and at risk of chronic disease	www.bchealthyliving.ca
BC Lupus Society	British Columbians who have lupus and their personal lupus networks, including their families, caregivers and friends	www.bclupus.org
BC Schizophrenia Society	People affected by schizophrenia and psychosis	www.bcscs.org
BC Schizophrenia Society – Nanaimo Branch	Friends and family of those living with a mental illness	www.bcscsnanaimo.org
BC Schizophrenia Society – Victoria Branch (Inc.)	People with psychotic disorders and their families/caregivers/supporters: schizophrenia, schizoaffective, bi-polar, major depression, first break psychosis.	www.bcscsvictoria.ca
Better Pharmacare Coalition	Patients represented by our member organizations	www.betterpharmacare.org
Bladder Health British Columbia Society	Overactive Bladder, Vaginal Health, Urinary Tract Infections, Benign Prostatic Hypertrophy and Bladder Cancer	www.bhbc.ca
British Columbia Lung Association	Patients suffering from lung disease	www.bc.lung.ca
C		
Canadian Arthritis Patient Alliance	Patients with all forms of arthritis	www.arthritispatient.ca
Canadian Breast Cancer Network (CBCN)	Canadians affected by breast cancer, including patients, survivors, caregivers and family members	www.cbcn.ca

Patient Group Name	Who the organization represents	Website (if available)
Canadian Cancer Society, BC and Yukon	Cancer patients and their families, in communities across BC and the Yukon, trying to prevent cancer and enhance the quality of life of those living with cancer	www.cancer.ca
Canadian Cancer Survivor Network	Cancer patients, survivors, caregivers, family members and other cancer organizations	www.survivornet.ca
The Canadian Continence Foundation	Urinary and Fecal Incontinent patients	www.canadiancontinence.ca
Canadian Council of the Blind	Blind and vision-impaired Canadians	www.ccbnational.net
Canadian Diabetes Association	People living with diabetes	www.diabetes.ca
Canadian Liver Foundation	Public and patients living with or at risk of liver disease	www.liver.ca
Canadian Organization for Rare Disorders	Patients, caregivers, and patient groups affected by rare disorders	www.raredisorders.ca
Canadian Patient Coalition	Charities and NGOs who represent patients	www.putpatientsfirst.ca
Canadian PBC Society	PBC patients, caregivers and families	www.pbc-society.ca
Canadian PKU & Allied Disorders Inc.	Families across Canada that have PKU or other rare disorders	www.canpku.org
Canadian Psoriasis Network	Canadians suffering with psoriatic disease. A national organization	www.canadianpsoriasisnetwork.com
Canadian Pulmonary Fibrosis Foundation	Pulmonary Fibrosis patients	www.cpff.ca
Canadian Skin Patient Alliance	Canadian skin patients	www.canadianskin.ca
The Canadian Society for Mucopolysaccharide & Related Diseases Inc.	Individuals and families affected by MPS and related diseases	www.mppsociety.ca
Canadian Treatment Action Council	People living with HIV and co-infected.	www.ctac.ca
Carcinoid-NeuroEndocrine Tumour Society Canada	NeuroEndocrine Tumour (NET) cancer patients	www.cnetscanada.org

Patient Group Name	Who the organization represents	Website (if available)
The Center for Epilepsy and Seizure Education in BC	People affected by epilepsy	www.esebc.ca
Centre for ADHD Awareness, Canada (CADDAC)	Those affective by ADHD	www.caddac.ca
Chronic Lymphocytic Leukemia Patient Advocacy Group (CLL PAG)	CLL patients and caregivers nationally and internationally	www.cllpag.ca
The Chronic Pain Association of Canada	Members in British Columbia who suffer pain	www.chronicpaincanada.com
Clean Air Coalition of BC	The member organizations represent the interests of persons in BC who are affected by heart (cardiac) and/or lung-related health issues	www.cleanaircoalitionbc.com
CNIB (Canadian National Institute for the Blind)	Blind and partially-sighted British Columbians	www.cnib.ca
Comox Valley People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Consumer Advocare Network	A national network of healthcare consumers organizations and individuals	http://survivornet.ca/en/partners/consumer_advocare_network
COPD Canada	Canadians with COPD (Chronic Obstructive Pulmonary Disease)	www.copdcanada.info
COPD Canada Patient Network	Patients in Canada with COPD	www.copdcanada.ca
Crohn's and Colitis Canada	People affected by Crohn's disease and ulcerative colitis, two main forms of Inflammatory Bowel Disease (IBD)	www.crohnsandcolitis.ca
Cystic Fibrosis Canada	Individuals with cystic fibrosis, their families and caregivers	www.cysticfibrosis.ca
D		
E		

Patient Group Name	Who the organization represents	Website (if available)
East Vancouver People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Eczema Society of Canada	Eczema patients and caregivers	https://eczemahelp.ca/
F		
FH Canada Patient Network	Patients with Familial Hypercholesterolemia (FH)	www.fhpatientcanada.org
Fraser Valley People in Pain Network Support Group	People living with persistent pain	www.pipain.com
G		
Gastrointestinal Society	Persons with gastrointestinal and liver diseases and disorders	www.badgut.org
H		
HAE Canada	Hereditary Angioedema (HAE) patients	www.haecanada.org
HeadWay Victoria Epilepsy & Parkinson's Centre	People with Parkinson's disease and Epilepsy	vepc.bc.ca
Heart and Stroke Foundation	People afflicted by heart disease and stroke (primary & secondary prevention and treatment)	www.heartandstroke.ca
HeartLife Foundation	Heart Failure Patients in Canada	www.heartlife.ca
Hep C Awareness.com	People affected by Hepatitis C	www.hepcawareness.com
Hepatitis CBC Hepatitis Education and Prevention Society	Those living with hepatitis C, and their family/friends/caregivers	www.hepcbc.ca
HS Aware	Patients, families and caregivers	www.hsaware.com
I		
J		
K		
Kelowna People in Pain Network Support Group	People living with persistent pain	www.pipain.com

Patient Group Name	Who the organization represents	Website (if available)
Kidney Foundation of Canada, BC Branch	7000 BC members & volunteers plus 240,000 British Columbians affected by chronic kidney disease	www.kidney.bc.ca
Kincaid People in Pain Network Support Group	People living with persistent pain	www.pipain.com
L		
Lonsdale Quay People in Pain Network Support Group	People living with persistent pain	http://www.pipain.com/12/post/2013/11/lonsdale-quay.html
Lupus Canada	People living with lupus and their caregivers, family and friends	www.lupuscanada.org
Lutheran Senior Citizens' Housing Society	Seniors requiring long term care in British Columbia	www.zionparkmanor.com
Lynn Valley Chronic Pain Support Group	People living with persistent pain	www.pipain.com
M		
MAGIC Foundation Canadian Division	Patients with endocrine disorders	www.magicfoundation.ca
Mental Health & Addictions Advisory Committee	Mental health consumers and family members	
Mollie Nye People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Mood Disorders Association of British Columbia	Those with Mood Disorders and other Mental Illnesses	www.mdabc.net
Multiple Sclerosis Society of Canada, BC & Yukon Division	People affected by MS	www.mssociety.ca/bc/default.htm
MS Society of Canada, Central Island Chapter	People with MS	www.mssociety.ca/centralisland
MS Society of Canada, Prince George Chapter	Multiple Sclerosis	www.mssociety.ca/princegeorge
MS Society of Canada, South Okanagan / Similkameen Chapter	People affected by MS	www.mssociety.ca

Patient Group Name	Who the organization represents	Website (if available)
MS Society of Canada, South Vancouver Island Chapter	People living with MS	www.mssociety.ca
MS Society of Canada – West Kootenay Chapter	People with MS, their caregivers, family members and the medical community who work with them	
N		
National Gaucher Foundation of Canada	Canadian Gaucher Patients	www.gauchercanada.ca
New Westminster People in Pain Men's Support Group	People living with persistent pain	www.pipain.com
North Shore Chronic Pain Support Group, under Chronic Pain Association of Canada	People living with pain	www.chronicpaincanada.com
O		
Osteoporosis Canada	People living with or at risk of osteoporosis	www.osteoporosis.ca
P		
Pacific Hepatitis C Network	People living with Hepatitis C.	www.pacifichepc.org
Parkinson Society British Columbia	People with Parkinson's and their families	www.parkinson.bc.ca
Patient Commando	Patient Commando is the leading independent group amplifying the patient voice in the healthcare relationship for any health condition	www.patientcommando.com
Patients Voices Network	Impact BC	https://patientvoicesbc.ca/
PCCN Chilliwack	Prostate Cancer patients	www.procansupport.com/support-groups/fraser-valley/chilliwack/
Pediatric Cancers Survivors Society of BC	Adult survivors of pediatric cancer	pcssbc.com
People in Pain Network	People living with persistent pain	www.pipain.com
Polycystic Kidney Disease (PKD) Foundation of Canada	Patients and their support systems	www.endpkd.ca

Patient Group Name	Who the organization represents	Website (if available)
Positive Living Fraser Valley	People living with HIV/AIDS and Hepatitis C	www.plfv.org
Positive Living Society of British Columbia	HIV-Positive British Columbians	http://positivelivingbc.org
Pulmonary Hypertension Association of Canada	Canadians affected by pulmonary hypertension	www.phacanada.ca
Q		
QuitNow Services	British Columbian tobacco users trying to quit	www.quitnow.ca
R		
Reaching Out MS Society of Salmon Arm	People with MS	www.intheshuswap.ca/romss
Rett Syndrome Society of BC	Those diagnosed with Rett Syndrome and their families/caregivers	www.rettbc.ca
S		
Save Your Skin Foundation	Patients and Caregivers	www.saveyourskin.ca
Scleroderma Association of BC	Scleroderma Patients in BC	www.sclerodermabc.ca
Scleroderma Society of Canada	Scleroderma patients and their families throughout Canada	www.scleroderma.ca
Sjogren's Society of Canada	People with Sjogren's syndrome and those seeking diagnosis	www.sjogrenscanada.org
Society for Diabetic Rights	People with Diabetes who use insulin	
Soft Bones Canada	All Patients, caregivers and their families across Canada who are affected by the rare metabolic bone disease Hypophosphatasia (HPP).	www.softbonescanada.ca
Steveston Chronic Pain Support Group	People living with persistent pain	http://stevestoncpsg.wordpress.com/
Stroke Recovery Association of BC	Stroke survivors in the community	www.strokerecoverybc.ca
Surrey Chronic Pain Support Group	People living with persistent pain	www.pipain.com
T		

Patient Group Name	Who the organization represents	Website (if available)
Trigeminal Neuralgia Association of Canada	People who suffer with trigeminal neuralgia; "The Suicide Disease"	www.tnac.org
Thyroid Cancer Canada	Canadians that have been affected by thyroid cancer	www.thyroidcancercanada.org
Tuberous Sclerosis Canada Sclérose Tubéreuse	Support and advocacy for individuals and families living with Tuberous Sclerosis Complex	www.tscanada.ca
Type 1 Together	Type 1 Diabetes	www.type1together.ca
U		
V		
Vancouver Acromegaly Support Group	Acromegaly	www.true-2-me.ca/vancouver
Vancouver Island Multiple Myeloma Support Group	Myeloma patients	www.myelomavancouverisland.ca
Vancouver West End People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Victoria Chronic Pain Support group	People living with persistent pain	www.pipain.com
Victoria Fairfield People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Victoria Hillside People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Victoria Human Exchange Society	People who are homeless, especially those with mental health and addiction challenges	www.humanx.org
W		
Why Choice Matters	People with mental illnesses and family members	www.whychoicematters.com
Williams Lake People in Pain Network Support Group	People living with persistent pain	www.pipain.com
Women's Health Initiative Network	Women with uterine health conditions including fibroids, contraceptive care, bladder and vaginal health concerns	http://\whin.ca

Patient Group Name	Who the organization represents	Website (if available)
X		
Y		
Youth People in Pain Network Support Group	Young people living with persistent pain	www.pipain.com
Z		