

# LIST OF REGISTERED PATIENT GROUPS

Last updated August 30, 2017

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Patient Group Name	Who the organization represents	Website (if available)
<b>A</b>		
<b>AboutFace Craniofacial Family Society</b>	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.	<a href="http://www.aboutface.ca">www.aboutface.ca</a>
<b>aHUS Canada/SHUa Canada</b>	Patients and caregivers and their families	<a href="http://www.ahuscanada.org">www.ahuscanada.org</a>
<b>Aldergrove People in Pain Network Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
<b>Alzheimer Society of BC</b>	People living with Alzheimer’s disease and other related dementias and their families	<a href="http://www.alzheimerbc.org">www.alzheimerbc.org</a>
<b>Aplastic Anemia and Myelodysplasia Association of Canada</b>	Persons with Aplastic Anemia, myelodysplasia and Paroxysmal Nocturnal Hemoglobinuria (PNH)	<a href="http://www.aamac.ca">www.aamac.ca</a>
<b>Arthritis Consumer Experts</b>	People living with arthritis	<a href="http://www.jointhealth.org">www.jointhealth.org</a>
<b>The Arthritis Society, BC &amp; Yukon Division</b>	People of all ages living with arthritis	<a href="http://www.arthritis.ca">www.arthritis.ca</a>
<b>ASIC (Access for Sight Impaired)</b>	Blind and Partially-Sighted British Columbians	<a href="http://www.asicbc.ca">www.asicbc.ca</a>
<b>Asthma Society of Canada – National Asthma Patient Alliance</b>	Patients with asthma and associated allergies across Canada	<a href="http://www.asthma.ca/napa">www.asthma.ca/napa</a>

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

Patient Group Name	Who the organization represents	Website (if available)
<b>Canadian Cancer Society, BC and Yukon</b>	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	<a href="http://www.cancer.ca">www.cancer.ca</a>
<b>Canadian Cancer Survivor Network</b>	Cancer patients, survivors, caregivers, family members and other cancer organizations	<a href="http://www.survivornet.ca">www.survivornet.ca</a>
<b>The Canadian Continence Foundation</b>	Urinary and Fecal Incontinent patients	<a href="http://www.canadiancontinence.ca">www.canadiancontinence.ca</a>
<b>Canadian Council of the Blind</b>	Blind and vision-impaired Canadians	<a href="http://www.ccbnational.net">www.ccbnational.net</a>
<b>Canadian Diabetes Association</b>	People living with diabetes	<a href="http://www.diabetes.ca">www.diabetes.ca</a>
<b>Canadian Liver Foundation</b>	Public and patients living with or at risk of liver disease	<a href="http://www.liver.ca">www.liver.ca</a>
<b>Canadian Organization for Rare Disorders</b>	Patients, caregivers, and patient groups affected by rare disorders	<a href="http://www.raredisorders.ca">www.raredisorders.ca</a>
<b>Canadian Patient Coalition</b>	Charities and NGOs who represent patients	<a href="http://www.putpatientsfirst.ca">www.putpatientsfirst.ca</a>
<b>Canadian PBC Society</b>	PBC patients, caregivers and families	<a href="http://www.pbc-society.ca">www.pbc-society.ca</a>
<b>Canadian PKU &amp; Allied Disorders Inc.</b>	Families across Canada that have PKU or other rare disorders	<a href="http://www.canpku.org">www.canpku.org</a>
<b>Canadian Pulmonary Fibrosis Foundation</b>	Pulmonary Fibrosis patients	<a href="http://www.cpff.ca">www.cpff.ca</a>
<b>Canadian Skin Patient Alliance</b>	Canadian skin patients	<a href="http://www.canadianskin.ca">www.canadianskin.ca</a>
<b>The Canadian Society for Mucopolysaccharide &amp; Related Diseases Inc.</b>	Individuals and families affected by MPS and related diseases	<a href="http://www.mpssociety.ca">www.mpssociety.ca</a>
<b>Canadian Treatment Action Council</b>	People living with HIV and co-infected.	<a href="http://www.ctac.ca">www.ctac.ca</a>
<b>Carcinoid-NeuroEndocrine Tumour Society Canada</b>	NeuroEndocrine Tumour (NET) cancer patients	<a href="http://www.cnetscanada.org">www.cnetscanada.org</a>

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

Patient Group Name	Who the organization represents	Website (if available)
<b>Eczema Society of Canada</b>	Eczema patients and caregivers	<a href="https://eczemahelp.ca/">https://eczemahelp.ca/</a>
<b>F</b>		
<b>FH Canada Patient Network</b>	Patients with Familial Hypercholesterolemia (FH)	<a href="http://www.fhpatientcanada.org">www.fhpatientcanada.org</a>
<b>Fraser Valley People in Pain Network Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
<b>G</b>		
<b>Gastrointestinal Society</b>	Persons with gastrointestinal and liver diseases and disorders	<a href="http://www.badgut.org">www.badgut.org</a>
<b>H</b>		
<b>HAE Canada</b>	Hereditary Angioedema (HAE) patients	<a href="http://www.haecanada.org">www.haecanada.org</a>
<b>HeadWay Victoria Epilepsy &amp; Parkinson's Centre</b>	People with Parkinson's disease and Epilepsy	<a href="http://vepc.bc.ca">vepc.bc.ca</a>
<b>Heart and Stroke Foundation</b>	People afflicted by heart disease and stroke (primary & secondary prevention and treatment)	<a href="http://www.heartandstroke.ca">www.heartandstroke.ca</a>
<b>HeartLife Foundation</b>	Heart Failure Patients in Canada	<a href="http://www.heartlife.ca">www.heartlife.ca</a>
<b>Hep C Awareness.com</b>	People affected by Hepatitis C	<a href="http://www.hepcawareness.com">www.hepcawareness.com</a>
<b>Hepatitis CBC Hepatitis Education and Prevention Society</b>	Those living with hepatitis C, and their family/friends/caregivers	<a href="http://www.hepcbc.ca">www.hepcbc.ca</a>
<b>HS Aware</b>	Patients, families and caregivers	<a href="http://www.hsaware.com">www.hsaware.com</a>
<b>I</b>		
<b>J</b>		
<b>K</b>		
<b>Kelowna People in Pain Network Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
<b>Kidney Foundation of Canada, BC Branch</b>	7000 BC members & volunteers plus 240,000 British Columbians affected by chronic kidney disease	<a href="http://www.kidney.bc.ca">www.kidney.bc.ca</a>

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<b>Kincaid People in Pain Network Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
<b>L</b>		
<b>Lonsdale Quay People in Pain Network Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com/12/post/2013/11/lonsdale-quay.html">http://www.pipain.com/12/post/2013/11/lonsdale-quay.html</a>
<b>Lupus Canada</b>	People living with lupus and their caregivers, family and friends	<a href="http://www.lupuscanada.org">www.lupuscanada.org</a>
<b>Lutheran Senior Citizens' Housing Society</b>	Seniors requiring long term care in British Columbia	<a href="http://www.zionparkmanor.com">www.zionparkmanor.com</a>
<b>Lynn Valley Chronic Pain Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
<b>M</b>		
<b>MAGIC Foundation Canadian Division</b>	Patients with endocrine disorders	<a href="http://www.magicfoundation.ca">www.magicfoundation.ca</a>
<b>Mental Health &amp; Addictions Advisory Committee</b>	Mental health consumers and family members	
<b>Mollie Nye People in Pain Network Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
<b>Mood Disorders Association of British Columbia</b>	Those with Mood Disorders and other Mental Illnesses	<a href="http://www.mdabc.net">www.mdabc.net</a>
<b>Multiple Sclerosis Society of Canada, BC &amp; Yukon Division</b>	People affected by MS	<a href="http://www.mssociety.ca/bc/default.htm">www.mssociety.ca/bc/default.htm</a>
<b>MS Society of Canada, Central Island Chapter</b>	People with MS	<a href="http://www.mssociety.ca/centralisland">www.mssociety.ca/centralisland</a>
<b>MS Society of Canada, Prince George Chapter</b>	Multiple Sclerosis	<a href="http://www.mssociety.ca/princegeorge">www.mssociety.ca/princegeorge</a>
<b>MS Society of Canada, South Okanagan / Similkameen Chapter</b>	People affected by MS	<a href="http://www.mssociety.ca">www.mssociety.ca</a>
<b>MS Society of Canada, South Vancouver Island Chapter</b>	People living with MS	<a href="http://www.mssociety.ca">www.mssociety.ca</a>

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

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<b>Positive Living Society of British Columbia</b>	HIV-Positive British Columbians	<a href="http://positivelivingbc.org">http://positivelivingbc.org</a>
<b>Pulmonary Hypertension Association of Canada</b>	Canadians affected by pulmonary hypertension	<a href="http://www.phacanada.ca">www.phacanada.ca</a>
<b>Q</b>		
<b>QuitNow Services</b>	British Columbian tobacco users trying to quit	<a href="http://www.quitnow.ca">www.quitnow.ca</a>
<b>R</b>		
<b>Reaching Out MS Society of Salmon Arm</b>	People with MS	<a href="http://www.intheshuswap.ca/romss">www.intheshuswap.ca/romss</a>
<b>Rett Syndrome Society of BC</b>	Those diagnosed with Rett Syndrome and their families/caregivers	<a href="http://www.rettbc.ca">www.rettbc.ca</a>
<b>S</b>		
<b>Save Your Skin Foundation</b>	Patients and Caregivers	<a href="http://www.saveyourskin.ca">www.saveyourskin.ca</a>
<b>Scleroderma Association of BC</b>	Scleroderma Patients in BC	<a href="http://www.sclerodermabc.ca">www.sclerodermabc.ca</a>
<b>Scleroderma Society of Canada</b>	Scleroderma patients and their families throughout Canada	<a href="http://www.scleroderma.ca">www.scleroderma.ca</a>
<b>Sjogren's Society of Canada</b>	People with Sjogren's syndrome and those seeking diagnosis	<a href="http://www.sjogrenscanada.org">www.sjogrenscanada.org</a>
<b>Society for Diabetic Rights</b>	People with Diabetes who use insulin	
<b>Soft Bones Canada</b>	All Patients, caregivers and their families across Canada who are affected by the rare metabolic bone disease Hypophosphatasia (HPP).	<a href="http://www.softbonescanada.ca">www.softbonescanada.ca</a>
<b>Steveston Chronic Pain Support Group</b>	People living with persistent pain	<a href="http://stevestoncpsg.wordpress.com/">http://stevestoncpsg.wordpress.com/</a>
<b>Stroke Recovery Association of BC</b>	Stroke survivors in the community	<a href="http://www.strokerecoverybc.ca">www.strokerecoverybc.ca</a>
<b>Surrey Chronic Pain Support Group</b>	People living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
<b>T</b>		
<b>Trigeminal Neuralgia Association of Canada</b>	People who suffer with trigeminal neuralgia; "The Suicide Disease"	<a href="http://www.tnac.org">www.tnac.org</a>



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

Patient Group Name	Who the organization represents	Website (if available)
Y		
<b>Youth People in Pain Network Support Group</b>	Young people living with persistent pain	<a href="http://www.pipain.com">www.pipain.com</a>
Z		