

Supplementary File 5: Names of patient groups, websites and

| | Name of group | Website | Notes | Number of pieces of information analyzed |
|----|---|---|--------------|---|
| 1 | AboutFace Craniofacial Family Society | www.aboutface.ca | | 3 |
| 2 | Advocacy for Canadian Childhood Oncology Research Network | http://www.curesforourkids.com | | 4 |
| 3 | aHUS Canada/SHUa | www.ahuscanada.org | | 8 |
| 4 | ALS Society of Canada | https://www.als.ca | | 8 |
| 5 | Aplastic Anemia and Myelodysplasia Association of Canada | www.aamac.ca | | 3 |
| 6 | Arthritis Consumer | www.jointhehealth.org | | 15 |
| 7 | Asthma Canada | https://asthma.ca | | 22 |
| 8 | Best Medicines Coalition | https://bestmedicinescoalition.org | | 10 |
| 9 | Bladder Cancer Canada | https://bladdercancercanada.org/en/ | | 8 |
| 10 | Brain Tumour Foundation of Canada | https://www.braintumour.ca | | 4 |
| 11 | Canadian Arthritis Patient Alliance | www.arthritispatient.ca | | 24 |
| 12 | Canadian Breast Cancer Network | https://www.cbcn.ca/en/ | | 10 |
| 13 | Canadian Cancer | www.cancer.ca | | 8 |
| 14 | Canadian Cancer Survivor Network | www.survivornet.ca | | 7 |
| 15 | Canadian Council of the Blind | www.ccbnational.net | | 7 |
| 16 | Canadian Digestive Health Foundation | https://cdhf.ca | | 2 |
| 17 | Canadian Epilepsy Alliance | http://www.canadianepilepsyalliance.org | | 3 |
| 18 | Canadian Hemophilia Society | https://www.hemophiliacsociety.ca | | 8 |
| 19 | Canadian Hospice Palliative Care | http://www.chpca.net | | 10 |
| 20 | Canadian Liver | www.liver.ca | | 7 |
| 21 | Canadian Mental Health Association | https://cmha.ca | | 3 |

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| 22 | Canadian Mesothelioma Foundation | http://cmfonline.org | | 1 |
| 23 | Canadian MPN Network | http://canadianmpnnetwork.ca | | 2 |
| 24 | Canadian Organization for Rare Disorders | www.raredisorders.ca | | 4 |
| 25 | Canadian Pain Coalition | https://www.facebook.com/CanadianPainCoalition/ | | 0 |
| 26 | Canadian PBC Society | www.pbc-society.ca | | 1 |
| 27 | Canadian Pemphigus and Pemphigoid Foundation | http://pemphigus.ca | | 1 |
| 28 | Canadian Pituitary Patient Network | https://canadianpituitary.org | | 0 |
| 29 | Canadian PKU & Allied Disorders Inc. | www.canpku.org | | 6 |
| 30 | Canadian Psoriasis Network | www.canadianpsoriasisnetwork.com | | 1 |
| 31 | Canadian Pulmonary Fibrosis Foundation | www.cfff.ca | | 2 |
| 32 | Canadian Skin Patient Alliance | www.canadianskin.ca | | 2 |
| 33 | Canadian Society for Mucopolysaccharide & Related Diseases Inc. | www.mppsociety.ca | | 1 |
| 34 | Canadian Society of Intestinal Research | https://www.badgut.org | | 1 |
| 35 | Canadian Spondylitis | http://www.spondyli.ca | | 1 |
| 36 | Canadian Treatment Action Council | www.ctac.ca | Website broken as of March 10, 2021 | Not applicable |
| 37 | Cancer Advocacy Coalition of Canada | http://www.canceradvocacy.ca | Name now changed to: Cancer Survivors | 1 |
| 38 | Carcinoid-NeuroEndocrine Tumour Society Canada | www.cnetscanada.org | | 1 |

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| 39 | Centre for ADHD Awareness, Canada (CADDAC) | www.caddac.ca | | 1 |
| 40 | Chronic Lymphocytic Leukemia Patient Advocacy Group (CLL) | www.clipag.ca | Name now changed to: CLL Canada | 3 |
| 41 | Chronic Myelogenous Leukemia Society of Canada | http://cmlsociety.org | Name now changed to: CML Society | 8 |
| 42 | Chronic Pain Association of Canada | www.chronicpaincanada.com | | 1 |
| 43 | CNIB (Canadian National Institute for the Blind) | www.cnib.ca | | 8 |
| 44 | Colorectal Cancer Canada | https://www.colorectalcancerCanada.com | | 11 |
| 45 | Consumer Advocare Network | http://survivornet.ca/en/partners/consumer_advocare_network | Website broken as of March 10, 2021 | Not applicable |
| 46 | COPD Canada | www.copdcanada.info | | 3 |
| 47 | COPD Canada Patient | www.copdcanada.ca | | 0 |
| 48 | Craig's Cause Pancreatic Cancer Society | http://www.craigsc ause.ca | | 1 |
| 49 | Crohn's and Colitis Canada | www.crohnsandcolitis.ca | | 4 |
| 50 | Cystic Fibrosis Canada | www.cysticfibrosis.ca | | 5 |
| 51 | Diabetes Canada (Canadian Diabetes Association) | www.diabetes.ca | | 24 |
| 52 | Eczema Society of Canada | https://eczemahelp.ca/ | | 19 |
| 53 | FH Canada Patient Network | https://thefhfoundation.org/global-fh-canada | Name now changed to: FH Foundation | 18 |
| 54 | Food Allergy Canada (Anaphylaxis Canada) | https://foodallergyCanada.ca | | 14 |
| 55 | Foundation Fighting Blindness | https://ffb.ca | New website: https://www.fightingblindness.ca | 18 |

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| 56 | Foundation for Prader-Willi Research Canada (FPWR Canada) | https://www.fpwr.ca | 2 |
| 57 | GIST Sarcoma Life Raft Group Canada | https://liferaftgroup.ca/welcome/ | 4 |
| 58 | HeartLife Foundation | www.heartlife.ca | 1 |
| 59 | Hep C Awareness.com | www.hepcawareness.com | 0 |
| 60 | HS Aware - Now appears to be HS | www.hsaware.com | 3 |
| | | | New website: |
| 61 | Huntington Society of Canada | https://www.huntingtonsociety.ca | 24 |
| 62 | Hypertension Canada | https://hypertension.ca/about-us/ | 7 |
| 63 | Kidney Cancer Canada | https://www.kidneycancercanada.ca | 13 |
| 64 | Leukemia & Lymphoma Society of Canada | https://www.llscanada.org | 9 |
| 65 | Lung Cancer Canada | http://www.lungcancercanada.ca | 6 |
| 66 | Lupus Canada | www.lupuscanada.org | 9 |
| 67 | Lymphoma Canada | https://www.lymphoma.ca | 22 |
| 68 | Mastocytosis Society Canada | https://www.mastocytosis.ca/en/ | 17 |
| 69 | Melanoma Network of Canada | https://www.melanomanetwork.ca | 35 |
| 70 | Millions Missing Canada | https://www.millionsmissingcanada.ca | 5 |
| 71 | MS Society of Canada | www.mssociety.ca | 74 |
| 72 | Myeloma Canada | https://www.myeloma.ca | 38 |
| 73 | National Gaucher Foundation of Canada | www.gauchercanada.ca | 10 |
| 74 | Neuroblastoma Canada | http://neuroblastoma.ca | 4 |
| 75 | Osteoporosis Canada | www.osteoporosis.ca | 19 |
| 76 | Ovarian Cancer Canada | https://ovariancanada.org | 21 |
| 77 | Pancreatic Cancer Canada | http://www.pancreaticcancercanada.ca | 20 |
| 78 | Parkinson Canada | https://www.parkinson.ca | 18 |

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| 79 | Patient Commando | www.patientcommando.com | | 8 |
| 80 | People in Pain Network | www.pipain.com | | 8 |
| 81 | Polycystic Kidney Disease (PKD) Foundation of Canada | www.endpkd.ca | Name now changed to: PKD Foundation of Canada | 5 |
| 82 | Prostate Cancer Canada | http://www.prostatecancer.ca | Now part of Canadian Cancer Society as of February 1, 2020 | Not applicable |
| 83 | Pulmonary Hypertension Association of Canada | www.phacanada.ca | | 15 |
| 84 | Rethink Breast Cancer | https://rethinkbreastcancer.com | | 8 |
| 85 | Robbie's Rainbow | http://robbiesrainbow.ca | | 6 |
| 86 | Sarcoma Cancer Foundation of Canada | http://sarcomacancer.ca | | 3 |
| 87 | Save Your Skin Foundation | www.saveyourskin.ca | | 4 |
| 88 | Scleroderma Society of Canada | www.scleroderma.ca | Name now changed to: Scleroderma Canada | 5 |
| 89 | Sjogren's Society of Canada | www.sjogrenscanada.org | | 6 |
| 90 | Soft Bones Canada | www.softbonescanada.ca | | 13 |
| 91 | The Canadian Continence Foundation | www.canadiancontinence.ca | | 9 |
| 92 | The Endometriosis Network | https://endometriosisnetwork.com | Name now changed to: The Endometriosis Network Canada | 4 |
| 93 | The Isaac Foundation | https://www.theisaacfoundation.com | | 0 |

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| 94 | Thyroid Cancer Canada | www.thyroidcancer.ca | 6 |
| 95 | Tourette Syndrome Foundation of Canada | https://tourette.ca | 14 |
| 96 | Trigeminal Neuralgia Association of Canada | www.tnac.org | 1 |
| 97 | Tuberous Sclerosis Canada Sclerose Tubereuse | https://www.tscanada.ca | 7 |
| 98 | Type 1 Together | www.type1together.ca | 4 |
| 99 | Wounds Canada (Canadian Association of Wound Care) | https://www.woundscanada.ca | 12 |
| 100 | Young Adult Cancer Canada | https://www.youngadultcancer.ca | 10 |