

PATIENT & FAMILY RESOURCES



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CLICK ON THE NAMES OF THE ORGANIZATION TO VISIT THEIR SITE & LEARN MORE!

WALKTALL

Disorders: Limb differences in children

Cost: Free

Resources offered: Support and information for patients and families, post-operation care resources, research information for limb differences

AMPUTEE COALITION

Disorders: Amputations

Cost: Free

Resources offered: Education and support for individuals with limb loss, mentorship/peer-matching

AMPUTEE COALITION OF BC SOCIETY

Disorders: Amputations

Cost: \$25 per year

Resources offered: Social and emotional support resources, information, assistance finding a prosthetist, financial aid

AMPUTEE COALITION OF CANADA

Disorders: Amputations

Cost: Free

Resources offered: Educational resources, provide opportunities, coping techniques, support systems, peer visitor program, quality of life support

BECKWITH WIEDMANN SUPPORT GROUP

Disorders: Beckwith Wiedmann

Cost: Free

Resources offered: Puts you in touch with parents who live near you

BIRTHMARK

Disorders: Arteriovenous malformation, haemangioma, vascular tumours, stalk bite, capillary malformation, venous malformation, glomuvenous malformation, combined vascular malformation, pigmented birthmarks, congenital melanocytic navels

Cost: Free

Resources offered: Information, support group events, peer support

BLOUNT'S DISEASE STRONG

Disorders: Blount's Disease

Cost: Free

Resources offered: Peer support, share resources and stories, ask and answer questions

CHILD GROWTH FOUNDATION

Disorders: Growth hormone deficiency, patients without a diagnosis, bone dysplasia, small for gestational age, russell silver syndrome, SHOX, sotos syndrome, IGF-1 deficiency, weavers syndrome - MORE LISTED [HERE](#)

Cost: \$25 per year in the UK, \$30 per year overseas

Resources offered: Updates on research, personal stories, helpline (parents who can help/support)

CLUBFOOT C.A.R.E.S

Disorders: Clubfoot

Cost: Free

Resources offered: Informational brochures, product recommendations, exercises, activities for children, and boot exchange/donations

CLUBFOOT SUPPORT

Disorders: Clubfoot

Cost: Free

Resources offered: Social support groups

CONGENITAL PSEUDOARTHROSIS SUPPORT GROUP

Disorders: Congenital Pseudoarthrosis

Cost: Free

Resources offered: Share stories, discuss medical advances, ask and answer questions, peer support



FIBULAR HEMIMELIA AND AMPUTATION AWARENESS

Disorders: Fibular Hemimelia and Amputations

Cost: Free

Resources offered: Info for parents, treatment options, peer support

FIXATOR SUPPORT GROUP

Disorders: External Fixator

Cost: Free

Resources offered: Share stories and advice, ask and answer questions, peer support

GENETIC ALLIANCE

Disorders: Achondroplasia, tibial hypoplasia, tibial/fibular hemimelia, hemiplegia, clubfoot, genu valgum, congenital amputation, hemihypertrophy, bowing of bones, tibial hypoplasia, arteriovenous malformations of brain, skeletal dysplasia, genu valgum and more

Cost: Free

Resources offered: Support and information for patients and families, opportunities for research

GROWING STRONGER SUPPORTING DWARFISM

Disorders: Dwarfism (achondroplasia)

Cost: Free

Resources offered: Information and online seminars, fundraising resources

HEMI HELP AND HOPE

Disorders: Hemihypertrophy

Cost: Free

Resources offered: Information and social support

HEMIHYPERTROPHY/HEMIHYPERPLASIA GLOBAL SUPPORT

Disorders: Hemihypertrophy/hemihyperplasia

Cost: Free

Resources offered: Resource for people to ask questions and connect with others

HUMAN GROWTH FOUNDATION

Disorders: Any disorders, diseases, and syndromes of growth abnormalities

Cost: Free

Resources offered: Research support, family education, education and training, links to online support groups on facebook

ILIZAROV/TAYLOR SPATIAL FRAME SUPPORT GROUP

Disorders: Patients having treatment with Ilizarov/taylor spatial frame

Cost: Free

Resources offered: Share stories and advice, support for patients and families, ask and answer questions

LEG LENGTH DISCREPENCY

Disorders: Caudal regression syndrome, leg length discrepancy

Cost: Free

Resources offered: Support & information for families

LIMBS 4 KIDS

Disorders: Children with limb deficiencies or anyone who underwent an amputation early in life, congenital femoral disease

Cost: Free

Resources offered: Information and social support for patients and families, help find and fund prosthetics and other equipment

LIMBS 4 LIFE

Disorders: Amputees + families

Cost: Free

Resources offered: Peer support program, resources and information, social events and activities, help with funding and prosthetics

LITTLE PEOPLE OF AMERICA

Disorders: Any disorders that cause short stature (top being achondroplasia, diastrophic dysplasia), skeletal dysplasia

Cost: Online resources free, \$55 per year for membership

Resources offered: Social support, medical support and information for patients and their families, scholarship and research grants

LITTLE PEOPLE OF BC

Disorders: Achondroplasia

Cost: Online resources free, \$25 for family membership

Resources offered: Resources (newsletters, information), sports opportunities, social activities, parent support group, workshops, scholarship opportunities and tutoring



THE MAGIC FOUNDATION

Disorders: Achondroplasia, growth factor deficiency, idiopathic short stature, intrauterine growth restriction, fibrous dysplasia, precocious puberty, turner syndrome, hemihypertrophy, hypochondroplasia, skeletal dysplasia and more

Cost: Free

Resources offered: Helps families learn about children's growth, support for undiagnosed children, peer-matching parents for support

NATIONAL ORGANIZATION FOR RARE DISORDERS

Disorders: Rare diseases

Cost: Free

Resources offered: Email and phone number for any questions, social media pages with support and contact information

ORTHOKIDS

Disorders: Common pediatric orthopaedic conditions

Cost: Free

Resources offered: Help finding a paediatric orthopaedist, question and answers, information and videos about the condition and treatment, links to other support groups

PATIENT ADVOCATE FOUNDATION

Disorders: Any disease/disorder that is not in the public spotlight / does not have enough awareness brought upon it

Cost: Free

Resources offered: Healthcare and financial support

PONSETI INTERNATIONAL

Disorders: Clubfoot

Cost: Free

Resources offered: Training healthcare workers to treat clubfoot in infants, educational resources (information for parents), support for healthcare providers, training internationally

POSTEROMEDIAL TIBIAL BOWING SUPPORT GROUP

Disorders: Posteromedial Tibial Bowing

Cost: Free

Resources offered: Support for parents, children, and adults to share experiences and concerns, answer each others questions and help each other

PROXIMAL FEMORAL FOCAL DEFICIENCY / CONGENITAL FEMORAL DEFICIENCY

Disorders: Proximal femoral focal deficiency, congenital femoral deficiency

Cost: Free

Resources offered: Information and peer support for families and patients

RARE DISEASES INTERNATIONAL

Disorders: Diseases affecting less than 1/2000 people.

Cost: First year free then 50 euros/year

Resources offered: Online seminars, articles, and information

STEPS WORLDWIDE

Disorders: Coxa Vara, Fibular Hemimelia, Hip dysplasia, Leg discrepancy, metatarsus adductus, perthes, PFFD, positional talipes/clubfoot, slipped upper femoral epiphysis, tibial hemimelia, vitamin D deficiency

Cost: Free

Resources offered: Support for patients and families, financial support to purchase specialized car seats for children

UNDERSTANDING DWARFISM

Disorders: Dwarfism (achondroplasia)

Cost: Free

Resources offered: Outreach program, support for families and patients

UPOPOLIS

Disorders: Any chronically ill or hospitalized youth 10-18 in North America

Cost: Free

Resources offered: Answers to medical questions, medical information and videos for children, volunteer opportunities and social support for children

THE WAR AMPS-CHAMPS

Disorders: Child amputees (under 18) + families

Cost: Free

Resources offered: Financial assistance towards artificial limbs and recreational devices, regional seminars, peer support for both children and parents, JUMPSTART program for children with multiple amputations,

