

ORGANIZATIONS, ASSOCIATIONS AND FOUNDATIONS This listing includes many voluntary health organizations which are skilled at information and referral at the local level. They provide a useful link for both health professionals and ventilator users in locating the resources needed to live at home with a ventilator. Many publish newsletters and magazines with occasional articles of interest to ventilator users. They are arranged alphabetically by country, then by organization.

International

AUSTRALIA

Australian Ventilator Users Network (AVUN)
www.avun.org.au

Muscular Dystrophy Foundation Australia
https://mdaustralia.org.au

SMA of Australia
www.sma-australia.org.au

Motor Neurone Disease Association, Inc.
www.mndawa.asn.au

Muscular Dystrophy Association
www.mda.org.au

**Muscular Dystrophy Association, Inc. of South Australia
& Northern Territory**
World Alliance of Neuromuscular Disorder Associations (WANDA)
www.mdasa.org.au

Spinal Cord Injuries Australia
https://scia.org.au

Spinal Injuries Association
www.spinal.com.au

DENMARK

Muskelsvindfonden
www.muskelsvindfonden.dk

EUROPE

European Alliance of Neuromuscular Disorders Association (EAMDA)
www.eamda.eu

FINLAND

European Alliance of Neuromuscular
www.lihastautiliitto.fi

FRANCE

Association Francaise contre les Myopathies (AFM)
www.afm-france.org

Association Lyonnaise de Logistique Posthospitalière (ALLP)
www.allp-sante.com

Association pour l'Assistance Respiratoire à Domicile (APARD)
Parc Euromédecine 2
www.apard.com

**Fédération ANTADIR (Association Nationale pour les Traitements
A Domicile, les Innovations et la Recherche)**
www.antadir.com

Journées Internationales de Ventilation à Domicile (JIVD)
www.jivd-france.com

GERMANY

**Association for Home Ventilation and Respiratory Weaning (AGH)
DIGAB e.V.**
www.heimbeatmung.de

Deutsche Gesellschaft für Muskelkranke e. V. (DGM)
www.dgm.org

Initiative Forschung und Therapie für SMA
www.initiative-sma.de

IRELAND

Irish Motor Neurone Disease Association
www.imnda.ie

Muscular Dystrophy Ireland
www.mdi.ie

ITALY

Associazione Famiglie SMA Onlus
www.famiglieasma.org

INFORESP-UILDM
www.inforesp.org

Muscular Dystrophy Italy
www.uildm.org

JAPAN

Japan ALS Association (JALSA)
www.alsjapan.org

The Japanese Respiratory Society
www.jrs.or.jp

Japanese Ventilator Users Network (JVUN)
www.jvun.org

Japanese Ventilator Users Parents Association (The BakuBaku Club)
www.bakubaku.org

MEXICO

**Familiares y Amigos de Enfermos de la Neurona Motora, A.C.
(FYADENMAC)**
www.fyadenmac.org

NETHERLANDS

Dutch Neuromuscular Diseases Association reniging Spierziekten
www.vsn.nl

International Pompe Association (IPA)
www.worldpompe.org

European NeuroMuscular Centre (ENMC)
www.enmc.org

NEW ZEALAND

Muscular Dystrophy Association NZ Inc.
www.mda.org.nz

SOUTH AFRICA

Muscular Dystrophy Foundation of South Africa
national@mdsa.org.za

SPAIN

Associacio Catalana de Malalties Neuromusculars (ASEM Catalunya)
www.asemcatalunya.com

European Respiratory Society (ERS)
www.ersnet.org

Polio Center
www.polio.ch

Schweizer Paraplegiker-Vereinigung
www.paranet.ch

UKRAINE

Families of SMA Ukraine
www.csma.org.ua

UNITED KINGDOM

Association for Respiratory Technology & Physiology
www.artp.org.uk

CMT United Kingdom
www.cmt.org.uk

International Alliance of ALS/MND Associations
www.alsmndalliance.org

Jennifer Trust for SMA
www.jtsma.org.uk

Motor Neurone Disease Association
www.mndassociation.org

Muscular Dystrophy Campaign
www.muscular-dystrophy.org

Respiratory Information for Spinal Cord Injury U.K.
www.risci.org.uk

Spinal Injuries Association
www.spinal.co.uk

TREAT-NMD
Institute of Human Genetics
www.treat-nmd.eu

VENEZUELA

Familias y Amigos de la Atrofia Muscular Espinal (FSMA Venezuela)
www.fame-fsma.org

United States

A

ALS Association (ALSA)
www.alsa.org

American Association for Respiratory Care (AARC)
www.aarc.org

American Association for Homecare (AAH)
www.aahomecare.org

American College of Chest Physicians (ACCP)
www.chestnet.org

American Sleep Apnea Association
www.sleepapnea.org

American Syringomyelia Alliance Project
www.syringo.org

American Thoracic Society (ATS)
www.thoracic.org

ARDS Foundation
www.ardsusa.org

C

Caregiver Action Network
www.caregiveraction.org

CCHS Family Network
www.cchsnetwork.org

Christopher Reeve Foundation (CRF)
www.christopherreeve.org

Cystic Fibrosis Foundation
www.cff.org

F

Families of Spinal Muscular Atrophy (FSMA)
www.curesma.org

Family Voices
www.familyvoices.org

FSH (Facioscapulohumeral) Society, Inc.
www.fshsociety.org

H

Hereditary Neuropathy Foundation (also Charcot-Marie-Tooth)
www.hnf-cure.org

K

Kennedy's Disease Association, Inc.
www.kennedysdisease.org

L

Les Turner ALS Foundation
www.lesturnerals.org

M

Muscular Dystrophy Association (MDA)
www.mda.org

Muscular Dystrophy Family Foundation

www.mdff.org

Myasthenia Gravis Foundation of America (MGFA)

www.myasthenia.org

N

**National Association for Medical Direction of Respiratory Care
(NAMDRC)**

www.namdrc.org

P

Paralyzed Veterans of America (PVA)

National Headquarters

www.pva.org

Parent Project for Muscular Dystrophy

www.parentprojectmd.org

Physician-Parent Caregivers (PPC)

<http://physicianparent.org>

R

Respiratory Nursing Society

www.respiratorynursingsociety.org

S

Sick Kids (Need) Involved People

SKIP of New York, Inc.

www.skipofny.org

U

United Spinal Association

www.spinalcord.org

V

Vent Kids of Alabama

www.facebook.com/search/top/?q=vent%20kids%20of%20alabama