

**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 (Faciocapulo-humeral) 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](http://www.mdff.org)

**Myasthenia Gravis Foundation of America (MGFA)**  
[www.myasthenia.org](http://www.myasthenia.org)

**N**

**National Association for Medical Direction of Respiratory Care  
 (NAMDRC)**  
[www.namdr.org](http://www.namdr.org)

**P**

**Paralyzed Veterans of America (PVA)**  
 National Headquarters  
[www.pva.org](http://www.pva.org)

**Parent Project for Muscular Dystrophy**  
[www.parentprojectmd.org](http://www.parentprojectmd.org)

**Physician-Parent Caregivers (PPC)**  
<http://physicianparent.org>

**R**

**Respiratory Nursing Society**  
[www.respiratorynursingsociety.org](http://www.respiratorynursingsociety.org)

**S**

**Sick Kids (Need) Involved People  
 SKIP of New York, Inc.**  
[www.skipofny.org](http://www.skipofny.org)

**U**

**United Spinal Association**  
[www.spinalcord.org](http://www.spinalcord.org)

**V**

**Vent Kids of Alabama**  
[www.facebook.com/search/top/?q=vent%20kids%20of%20alabama](https://www.facebook.com/search/top/?q=vent%20kids%20of%20alabama)