

**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](http://www.mda.org.nz)

## SOUTH AFRICA

**Muscular Dystrophy Foundation of South Africa**  
[national@mdsa.org.za](mailto:national@mdsa.org.za)

## SPAIN

**Associacio Catalana de Malalties Neuromusculars (ASEM Catalunya)**  
[www.asemcatalunya.com](http://www.asemcatalunya.com)

**European Respiratory Society (ERS)**  
[www.ersnet.org](http://www.ersnet.org)

**Polio Center**  
[www.polio.ch](http://www.polio.ch)

**Schweizer Paraplegiker-Vereinigung**  
[www.paranet.ch](http://www.paranet.ch)

## UKRAINE

**Families of SMA Ukraine**  
[www.csma.org.ua](http://www.csma.org.ua)

## UNITED KINGDOM

**Association for Respiratory Technology & Physiology**  
[www.artp.org.uk](http://www.artp.org.uk)

**CMT United Kingdom**  
[www.cmt.org.uk](http://www.cmt.org.uk)

**International Alliance of ALS/MND Associations**  
[www.alsmndalliance.org](http://www.alsmndalliance.org)

**Jennifer Trust for SMA**  
[www.jtsma.org.uk](http://www.jtsma.org.uk)

**Motor Neurone Disease Association**  
[www.mndassociation.org](http://www.mndassociation.org)

**Muscular Dystrophy Campaign**  
[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

**Respiratory Information for Spinal Cord Injury U.K.**  
[www.risci.org.uk](http://www.risci.org.uk)

**Spinal Injuries Association**  
[www.spinal.co.uk](http://www.spinal.co.uk)

**TREAT-NMD**  
Institute of Human Genetics  
[www.treat-nmd.eu](http://www.treat-nmd.eu)

## VENEZUELA

**Familias y Amigos de la Atrofia Muscular Espinal (FSMA Venezuela)**  
[www.fame-fsma.org](http://www.fame-fsma.org)

## United States

### A

**ALS Association (ALSA)**  
[www.alsa.org](http://www.alsa.org)

**American Association for Respiratory Care (AARC)**  
[www.aarc.org](http://www.aarc.org)

**American Association for Homecare (AAH)**  
[www.aahomecare.org](http://www.aahomecare.org)

**American College of Chest Physicians (ACCP)**  
[www.chestnet.org](http://www.chestnet.org)

**American Sleep Apnea Association**  
[www.sleepapnea.org](http://www.sleepapnea.org)

**American Syringomyelia Alliance Project**  
[www.syringo.org](http://www.syringo.org)

**American Thoracic Society (ATS)**  
[www.thoracic.org](http://www.thoracic.org)

**ARDS Foundation**  
[www.ardsusa.org](http://www.ardsusa.org)

### C

**Caregiver Action Network**  
[www.caregiveraction.org](http://www.caregiveraction.org)

**CCHS Family Network**  
[www.cchsnetwork.org](http://www.cchsnetwork.org)

**Christopher Reeve Foundation (CRF)**  
[www.christopherreeve.org](http://www.christopherreeve.org)

**Cystic Fibrosis Foundation**  
[www.cff.org](http://www.cff.org)

### F

**Families of Spinal Muscular Atrophy (FSMA)**  
[www.curesma.org](http://www.curesma.org)

**Family Voices**  
[www.familyvoices.org](http://www.familyvoices.org)

**FSH (Facioscapulohumeral) Society, Inc.**  
[www.fshsociety.org](http://www.fshsociety.org)

### H

**Hereditary Neuropathy Foundation (also Charcot-Marie-Tooth)**  
[www.hnf-cure.org](http://www.hnf-cure.org)

### K

**Kennedy's Disease Association, Inc.**  
[www.kennedysdisease.org](http://www.kennedysdisease.org)

### L

**Les Turner ALS Foundation**  
[www.lesturnerals.org](http://www.lesturnerals.org)

### M

**Muscular Dystrophy Association (MDA)**  
[www.mda.org](http://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.namdrc.org](http://www.namdrc.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)