

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)

PO Box 211
Fairfield, Victoria 3078
+61 3 9844 2573 (tel & fax)
aggp@connexus.net.au, www.avun.org.au

Duchenne Foundation for Boys with Muscular Dystrophy

deborah.robins@duchennefoundation.org.au
www.parentproject.org.au

SMA of Australia

129 Moondarra Drive
Berwick, Victoria 3806
+61 3 8786 7521
admin@smaaustralia.com
www.smaaustralia.com

Motor Neurone Disease Association, Inc.

Center for Neurological Support, The Niche
B/11 Aberdare Rd
Nedlands, West Australia 6009
+61 8 9346 7355, +61 8 9346 7332 fax
www.mndawa.asn.au

Muscular Dystrophy Association

111 Boundary Rd
North Melbourne, Victoria 3051
+61 3 9320 9555, +61 3 9320 9595 fax
info@mda.org.au, www.mda.org.au

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

GPO 414
Adelaide, South Australia 5001
+61 8 8234 5266, +61 8 8234 5866 fax
info@mdasa.org.au, www.mdasa.org.au

Spinal Cord Injuries Australia

PO Box 397
Matraville, New South Wales 2036
+61 2 9661 8855, +61 2 9661 9598 fax
office@scia.org.au
www.spinalcordinjuries.com.au

Spinal Injuries Association

L1/109 Logan Road
Woolloongabba 4102
PO Box 5651 West End 4101
Brisbane, Queensland
+61 7 3391 2044, +61 7 3391 2088 fax
enquiries@spinal.com.au
www.spinal.com.au

Xavier Children's Support Network

Northside:
1935 Gympie Rd
Bald Hills, Queensland 4036
+61 7 3261 6950, +61 3261 6055 fax
Southside:
284 Pine Mountain Rd, Mt. Gravatt East
Brisbane, Queensland 4122
+61 7 3216 8811, +61 7 3216 8778 fax
www.xcsn.org

BELGIUM

Association des Insuffisants Respiratoires

Centre Hospitalier de l'Ardenne
B-6680 Ste-Ode
+32 84 225 280, +32 84 225 284 fax
freddy.smeets@cha.be

CANADA

ALS Society of Canada

3000 Steeles Ave East Ste 200
Markham, Ontario L3R 4T9
800-267-4257, 905-248-2052
905-248-2019 fax
www.als.ca

Canadian Society of Respiratory Therapists

102-1785 Alta Vista Dr
Ottawa, Ontario K1G 3Y6
800-267-3422, 613-731-3164
613-521-4314 fax, www.csrft.com

Families of SMA Canada

PO Box 97
Rivers, Manitoba R0K 1X0
800-866-0016 www.curesma.ca

Muscular Dystrophy Association of Canada

2345 Yonge St Ste 900
Toronto, Ontario M4P 2E5
866-MUSCLE-8, 416-488-0030
416-488-7523 fax
info@muscle.ca, www.muscle.ca

Neil Squire Society

2250 Boundary Rd Ste 220
Burnaby, British Columbia V5M 3Z3
604-473-9363, 604-473-9364 fax
info@neilsquire.ca, www.neilsquire.ca

CHINA

Families of SMA Charitable Trust

Room 1402, 14/F, SUP Tower
83 King's Road, North Point
Hong Kong
+852 2811 1767, +852 2510 7199 fax
info@fsma.org.hk, www.fsma.org.hk

DENMARK

Muskelsvindfonden

Kongsvang Allé 23
DK-8000 Århus C
+45 89 48 2222, +45 8948 22 12 fax
reception@muskelsvindfonden.dk
www.muskelsvindfonden.dk

FINLAND

Finnish Muscular Disorders Association

Läntinen Pitkätie 35
FIN-20100 Turku
+358 2 273 9700, +358 2 273 9701 fax
lihastautiliitto@lihastautiliitto.fi
www.lihastautiliitto.fi

FRANCE

Association d'entraide des Polios et Handicapés (ADEP – Assistance)

194, rue d'Alésia
F-75014 Paris
+33 1 45 45 40 30
+33 1 45 45 38 63 fax
adep2@wanadoo.fr, www.adep-siege.org
2 rue Benoit Malon
F-92150 Suresnes
+33 1 46 97 12 87
www.adep.asso.fr

Association Française contre les Myopathies (AFM)

1, rue de L'Internationale
BP 59 91002 Evry Cedex
+33 1 69 47 28 28
+33 1 69 13 21 22 fax
jpaulus@mail.afm.genethon.fr
www.afm-france.org

Association Lyonnaise de Logistique Posthospitalière (ALLP)

39, Bd Ambroise Paré
69371 Lyon Cedex 08
+33 4 72 10 67 89
+33 4 72 00 04 66 fax
contact@allp-sante.com
www.allp-sante.com

Association pour l'Aide aux Insuffisants Respiratoires (AIR) de Bretagne

ZAC Atalante Villejean
8, rue Jean-Louis Bertrand
F-35000 Rennes
+33 2 23 46 44 20
+33 2 23 46 74 05 fax
contact@air-de-bretagne.asso.fr
www.air-de-bretagne.asso.fr

Association pour l'Assistance Respiratoire à Domicile (APARD)

Parc Euromédecine 2
Rue de Chambert CS 50003
F-34186 Montpellier Cedex 4
+33 800 0273, +33 800 027 273 fax
mail@apard.com, www.apard.com

Association pour l'Insertion des Grands Handicapés Respiratoires et Moteurs (APIGHREM)

4 Rue des Ourgouillous
ZAE Les Avants 34270
St Mathieu de Trévières
+33 4 67 55 16 00
+33 4 67 55 10 75 fax
apighrem@wanadoo.fr, www.apighrem.com

DDS Franche-Comté

1, bis Bd Fleming, BP 12085
F-25051 Besançon Cedex 5
+33 3 81 52 51 25
+33 3 81 51 75 11 fax
dds@dds-fc.org, www.dds-fc.org

Fédérative ANTADIR

66, Bd Saint-Michel
F-75006 Paris
+33 1 56 81 40 60
+33 1 56 81 40 61 fax
antadir@antadir.com, www.antadir.com

Journées Internationales de Ventilation à Domicile (JIVD)

Service de Réanimation Médicale
et d'Assistance Respiratoire
Hôpital de la Croix Rousse
93, Grande Rue de la Croix Rousse
F-69317 Lyon Cedex 04
+33 4 78 39 08 43
+33 4 78 39 58 63 fax
Brigitte.Hautier@free.fr, www.jivd-france.com

GERMANY**Association for Home Ventilation and Respiratory Weaning (AGH)**

DIGAB e.V.
Pappelweg 5
D-37120 Bovenden
www.heimbeatmung.de
windischw@kliniken-koeln.de

Deutsche Gesellschaft für Muskelkranke e. V. (DGM)

Horst Ganter, Im Moos 4
D-79112 Freiburg
+49 07665/9447-0
+49 07665/9447-20 fax
info@dgm.org, www.dgm.org

Initiative Forschung und Therapie für SMA

Bohlenweg 21
D-63739 Aschaffenburg
+49 60 21 9 50 56
info@initiative-sma.de, www.initiative-sma.de

IRELAND**Irish Motor Neuron Disease Association**

Coleraine House, Coleraine Street
Dublin 7
FreePhone 800 403 403
+353 1 873 0422, +353 1 873 1409 fax
info@imnda.ie, www.imnda.ie

Muscular Dystrophy Ireland

71/72 North Brunswick St
Dublin 7
+353 1 8721501, +353 1 8724482 fax
info@mdi.ie, www.mdi.ie

ISRAEL**Families of SMA Israel**

+972 50-5219401
www.fsmaail.co.il

ITALY**Associazione Famiglie SMA Onlus**

Via Camaldoli, 64
20138 Milano
+39 0272095 876
www.famiglie.sma.org

INFORESP-UILDM

Via Lampedusa 11/a
I-20141 Milano
+39 02 2360084 (tel & fax)
info@inforesp.org, www.inforesp.org

**Muscular Dystrophy Italy
Unione Italiana Lotta alla Distrofia Muscolare (UILDM)**

Via P.P. Vergerio, 19
35126 Padova
+39 49 8021001/757361
+39 49 757033 fax
redazione@uildm.it, www.uildm.org

JAPAN**Japan ALS Association (JALSA)**

7-103 Nando-cho, Shinjuku-ku
Tokyo 162-0837
+81 3 3234-9155, +81 3 3234-9156 fax
jalsa@jade.dti.ne.jp, www.alsjapan.org

The Japanese Respiratory Society

Nichinai Bldg, 7F, 3-28-8
Hongo, Bunkyo-ku, Tokyo 113-0033
+81 3-5805-3553, +81 3-5805-3554 fax
info@jrs.or.jp, www.jrs.or.jp

Japanese Ventilator Users Network (JVUN)

Nyu Nangou San Haitu 1F
Nangou douri 14tyoume Minami 2-2
Shiroishi Ward
Sapporo City, Hokkaido 003-0021
+81 11 868-3306 (tel & fax)
info@jvun.org, www.jvun.org

Japanese Ventilator Users Parents Association (The BakuBaku Club)

3-11-23-101 Itakano
Higashiyodogawa-ku
Osaka 533-0001
+81 072-724-2007
bakubaku@onp.or.jp, www.bakubaku.org

MALTA**European Alliance of NeuroMuscular Disorders Associations (EAMDA)**

c/o Muscular Dystrophy Group of Malta
4, Gzira Road
Gzira GZR 04 Malta
+356 21 346688
+356 21 318024 fax
eamda@hotmail.com, www.eamda.net

MEXICO**ADELA A.C. (ALS)**

Puerto de Cartagena # 308
Colonia Arbide
Léon, Guanajuato 37360
+52 477 713-7551
eduardo_castro@msn.com

Familiares y Amigos de Enfermos de la Neurona Motora, A.C. (FYADENMAC)

Enrique Farman 164-B
Col Aviación Civil
CP 15740 Mexico DF
+52 5115-1285, +52 5115-1286 fax
administracion@fyadenmac.com
www.fyadenmac.org

NETHERLANDS**Dutch Neuromuscular Diseases Association reniging Spierziekten Nederland (VSN)**

Lt. Gen. van Heutszlaan 6
NL-3743 JN Baarn
+31 35 5480480
vsn@vsn.nl, www.vsn.nl

International Pompe Association (IPA)

Lt. Gen. Van Heutszlaan 6
NL-3743 JN Baarn
+31 35 5480461, +31 35 5480499 fax
www.worldpompe.org

European NeuroMuscular Centre (ENMC)

Lt. Gen. van Heutszlaan 6
NL-3743 JN Baarn
+31 35 5480481, +31 35 5480499 fax
info@enmc.org, www.enmc.org

NEW ZEALAND

Muscular Dystrophy Association NZ Inc.
PO Box 16-238
Sandringham, Auckland 1030
+64 800-800-337
info@mda.org.nz, www.mda.org.nz

SOUTH AFRICA

**Muscular Dystrophy Foundation
of South Africa**
PO Box 1535
Pinegowrie 2123
+27 011 789-7634 (tel & fax)
national@mdsa.org.za, www.mdsa.org.za

SPAIN

**Associacio Catalana de Malalties
Neuromusculares (ASEM Catalunya)**
Montsec, 20-22
E-08030 Barcelona
+34 93 274 49 83
+34 93 274 13 92 fax
asemcatalunya@telefonica.net
www.asemcatalunya.com

SWITZERLAND

**European Respiratory Care
Association (ERCA)**
11 Chemin Beau Site
CH-1004 Lausanne
kathleen.grant@eurorespicare.com
www.eurorespicare.com

European Respiratory Society (ERS)
4, Ave Sainte-Luce
CH-1003 Lausanne
+41 21 213 01 01
+41 21 213 01 00 fax
info@ersnet.org, www.ersnet.org

Polio Center
Kollerweg 18
CH-3006 Berne
+41 31 972 17 09
mleh@swissonline.ch, www.polio.ch

**Schweizer Paraplegiker-Vereinigung
Swiss Paraplegic Center**
Kantonsstrasse 40
CH-6207 Nottwil
+41 41 939 54 00
spv@paranet.ch, www.paranet.ch

UKRAINE

Families of SMA Ukraine
Nikitina str. 13, flat 15
Kharkiv, Ukraine 60150
+38 50 364 0673
info@csmua.org.ua, www.csmua.org.ua

UNITED KINGDOM

**Association for Respiratory Technology
& Physiology**
Suite 4, Sovereign House
Gate Lane, Boldmere
Sutton Coldfield, Birmingham B73 5TT
+44 0845 226 3062
+44 121 355 2420 fax
admin@artp.org.uk, www.artp.org.uk

CMT United Kingdom
98 Broadway, Bournemouth
Southbourne, England BH6 4EH
+44 800 652-6316
info@cmt.org.uk, www.cmt.org.uk

International Alliance of ALS/MND Associations

PO Box 246
Northampton, England NN1 2PR
+44 1604 611 821
+44 1604624726 fax
alliance@alsmndalliance.org
www.alsmndalliance.org

Jennifer Trust for SMA
Elta House, Birmingham Road
Stratford-upon-Avon
Warwickshire, England CV37 0AQ
+44 0800 975 3100
+44 1789 268 371 fax
jennifer@jtsma.org.uk, www.jtsma.org.uk

Lane-Fox Respiratory Unit Patients Association

St. Thomas Hospital
York House (second floor)
199, Westminster Bridge Rd
London, England SE1 7UT
+44 20 7261 0511
+44 20 7928 7919 fax
lanefoxpatients.assoc@virgin.net

Muscular Dystrophy Campaign
61 Southwark Street
London, England SE1 0HL
800-652-6352 freephone
+44 20 7803 4800
+44 20 7401 3495 fax
info@muscular-dystrophy.org
www.muscular-dystrophy.org

**Scottish Motor Neurone
Disease Association**
76 Firhill Rd
Glasgow, Scotland G20 7BA
+44 141 945 1077
+44 141 945 2578 fax
info@scotmnd.co.uk, www.scotmnd.org.uk

Spinal Injuries Association
SIA House
2 Trueman Place, Oldbrook
Milton Keynes, England MK6 2HH
+44 845 6786633
+44 800 980 0501
+44 845070 6911 fax
sia@spinal.co.uk, www.spinal.co.uk

TREAT-NMD

Institute of Human Genetics
University of Newcastle upon Tyne
International Centre for Life
Newcastle upon Tyne
NE1 3BZ England, United Kingdom
+44 191 241 8605
+44 191 241 8770 fax, www.treat-nmd.eu

VENEZUELA

**Familias y Amigos de la Atrofia
Muscular Espinal (FSMA Venezuela)**
+58 412 364 2685
fame@fame-fsma.org, www.fame-fsma.org

United States

ALS Association (ALSA)
27001 Agoura Rd Ste 150
Calabasas Hills, CA 91301-5104
800-782-4747, 818-880-9007
818-880-9006 fax, www.alsa.org

**American Association for Respiratory
Care (AARC)**
9425 N MacArthur Blvd Ste 100
Irving, TX 75063-4706
972-243-2272, 972-484-2720 fax
info@aarc.org, www.aarc.org

**American Association for Homecare
(AAH)**
2011 Crystal Dr Ste 725
Arlington, VA 22202
703-836-6263, 703-836-6730 fax
info@aahomecare.org
www.aahomecare.org

**American College of Chest
Physicians (ACCP)**
3300 Dundee Rd
Northbrook, IL 60062-2348
800-343-2227, 847-498-1400
847-498-5460 fax
accp@chestnet.org, www.chestnet.org

American Sleep Apnea Association
6856 Eastern Ave, NW, Ste 203
Washington, DC 20012
202-293-3650, 202-293-3656 fax
asaa@sleepapnea.org, www.sleepapnea.org

American Syringomyelia Alliance Project
PO Box 1586
Longview, TX 75606-1586
800-272-7282, 903-236-7079
800-ASA-P282 fax
syringo@syringo.org, www.syringo.org

American Thoracic Society (ATS)
61 Broadway
New York, NY 10006-2755
212-315-8600, 212-315-6498 fax
www.thoracic.org

ARDS Foundation

3100 Dundee Ste 402
Northbrook, IL 60062
312-749-7047, 847-272-5499 fax
info@ardsusa.org, www.ardsusa.org

CCHS Family Network

71 Maple St
Oneonta, NY 13820-1561
607-431-4351 fax
VanderlaanM@hartwick.edu
www.cchsnetwork.org

**Christopher and Dana Reeve
Paralysis Resource Center**

636 Morris Turnpike Ste 3A
Short Hills, NJ 07078
800-539-7309, 973-467-8270 ext 204
973-467-9845 fax
info@paralysis.org, www.paralysis.org

Christopher Reeve Foundation (CRF)

636 Morris Turnpike Ste 3A
Short Hills, NJ 07078
800-225-0292, 973-912-9433 fax
www.christopherreeve.org

**Communication Independence for
Neurologically Impaired, Inc. (CINI)**

PO Box 263
Manorville, NY 11949
631-878-0642, 631-878-8333 fax
cini@cini.org, www.cini.org

Cystic Fibrosis Foundation

6931 Arlington Rd, 2nd Floor
Bethesda, MD 20814
800-344-4823, 301-951-4422
301-951-6378 fax
info@cff.org, www.cff.org

Families of SMA

PO Box 196
Libertyville, IL 60048-0196
800-886-1762, 847-367-7620
847-367-7623 fax
sma@fsma.org, www.curesma.org

Family Support Network

181 W Orangethorpe Ave Ste D
Placentia, CA 92870
714-854-7762, 714-854-7765 fax
fsnca@sbcglobal.net
www.familysupportnetworkca.com

Family Voices

2340 Alamo SE Ste 102
Albuquerque, NM 87106
888-835-5669, 505-872-4774
505-872-4780 fax
kidshealth@familyvoices.org
www.familyvoices.org

FSH (Facioscapulohumeral) Society, Inc.

64 Grove St
Watertown, MA 02472
617-658-7878, 617-658-7879 fax
info@fshsociety.org, www.fshsociety.org

Hereditary Neuropathy Foundation

(also Charcot-Marie-Tooth)
PO Box 287103
New York, NY 10128
917-648-6971
info@hnf-cure.org, www.hnf-cure.org

Kennedy's Disease Association, Inc.

PO Box 1105
Coarsegold, CA 93614-1105
559-658-5950
info@kennedysdisease.org
www.kennedysdisease.org

Les Turner ALS Foundation

5550 W Touhy Ave Ste 302
Skokie, IL 60077-3254
888-ALS-1107 tollfree, 847-679-3311
847-679-9109 fax
info@lesturnerals.org, www.lesturnerals.org

Muscular Dystrophy Association (MDA)

3300 E Sunrise Dr
Tucson, AZ 85718
800-572-1717, 520-529-5300 fax
mda@mdausa.org, www.mda.org

Muscular Dystrophy Family Foundation

7220 US 31 South
Indianapolis, IN 46227
800-544-1213, 317-923-MDFF
317-923-6334 fax, www.mdff.org

**Myasthenia Gravis Foundation
of America (MGFA)**

355 Leying Ave, 15th Floor
Lexington, NY 10017
800-541-5454, 212-297-2156
212-370-9047 fax
mgfa@myasthenia.org, www.myasthenia.org

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

8618 Westwood Center Dr Ste 210
Vienna, VA 22182-2222
703-752-4359, 703-752-4360 fax
ExecOffice@namdrc.org, www.namdrc.org

National Family Caregivers Association

10400 Connecticut Ave Ste 500
Kensington, MD 20895-3944
800-896-3650, 301-942-6430
301-942-2302 fax
info@thefamilycaregiver.org
www.thefamilycaregiver.org

**National Spinal Cord Injury
Association (NSCIA)**

1 Church St # 600
Rockville, MD 20850
800-962-9629, 301-214-4006
301-990-0445 fax
info@spinalcord.org, www.spinalcord.org

Nemaline Myopathy Foundation (NMF)

PO Box 5937
Round Rock, TX 78683-5937
512-388-7985
www.nemalinefoundation.org

Northwest Assistive Breathing Center

University of Washington Medical Center
1959 NE Pacific St, Campus Box 356522
Seattle, WA 98195-6522
206-598-5864, boitano@u.washington.edu

Paralyzed Veterans of America (PVA)

National Headquarters
801 18th St NW
Washington, DC 20006-3517
800-424-8200, 800-795-4327 TTY
info@pva.org, www.pva.org

Parent Project for Muscular Dystrophy

158 Linwood Plaza, Ste 220
Fort Lee, NJ 07024
800-714-5437, 201-944-9985 fax
pat@parentprojectmd.org
www.parentprojectmd.org

Physician-Parent Caregivers (PPC)

9700 Great Seneca Highway, Ste 258
Rockville, MD 20850
301-983-0406, 240-238-2601 fax
http://physicianparent.org

Pierre Robin Network

3604 Biscayne St
Quincy, IL 62305-4740
info@pierrerobin.org, www.pierrerobin.org

Post-Polio Health International (PHI)

4207 Lindell Blvd # 110
Saint Louis, MO 63108-2930
314-534-0475, 314-534-5070 fax
info@post-polio.org, www.post-polio.org

Respiratory Nursing Society

PO Box 980567
Richmond, VA 23298
www.respiratorynursingsociety.org

RespiteMatch

PO Box 884
Rex, GA 30273
678-884-0281, info@RespiteMatch.com
www.RespiteMatch.com

Sick Kids (Need) Involved People

SKIP of New York, Inc.
213 W 35th St 11th Flr
New York, NY 10001-1903
212-268-5999, 212-268-7667 fax
www.skipofny.org

Vent Kids of Alabama

4073 McClendon Chapel Rd
Bessemer, AL 35022
205-370-9605, 205-424-2928
karabishop@ventkidsalabama.com
www.ventkidsalabama.com/index.htm