

International Patient Advocacy Organizations

Country / Region	Organization	Email - General	Telephone	Website(s)
Africa	African Alliance for Rare Diseases	info@africa-rare.org	Telephone: +27 010 594 3844	http://www.africa-rare.org/ & https://africa-rare.org/wp-content/uploads/2016/10/Terms-of-Reference-Africa-Rare.org_.pdf
Albania	Rare Diseases Association Albania	http://rda-al.com/en/contact/	Telephone: 355 69 720 3644	http://rda-al.com/en/
Algeria	Shifa Association of NeuroMuscular Diseases	shifa@live.fr	Telephone: +213 773744620	http://shifadz.wix.com/asso
Algeria	Algerian Alliance Against Rare Diseases	aamrare@aol.com	Telephone: +213 773744620	http://aamrdz.wixsite.com/rare
Argentina	FAME Argentina - Familias de Atrofia Muscular Espinal (Families of SMA)	fameargentina@gmail.com	Telephone: +54 9 (11) 2164-8107	http://www.fameargentina.com.ar/ & https://www.facebook.com/FAME-Argentina-216974078365467/?eid=ARD57tAy68GLwOI0o1SyT7EygnyLNSFNJlI6QxXud3yNeP804pHJufWyXUFMujHeytGYTAK1pWf7jGjw
Argentina	ALAPA - Alianza Argentina de Pacientes (Patient Alliance)	info@alianzapacientes.org	Telephone: 54 911 2266 3101	http://alianzapacientes.org/ & https://www.facebook.com/somosalapa/
Argentina	FADEPOF - Federación Argentina de Enfermedades Poco Frecuentes (Argentina Federation for Rare Diseases)	info@fadepof.org.ar & https://fadepof.org.ar/contacto.php	Telephone: +54 9 (11) 3 901-221	http://fadepof.org.ar/
Asia	SMA Asia	info@smaasia.org		https://www.smaasia.org/
Australia	Spinal Muscular Atrophy Australia Inc.	reception@smaaustralia.org.au		https://smaaustralia.org.au/
Australia	Australasian Neuromuscular Network	jointheANN@gmail.com		http://www.ann.org.au/
Australia	Genetic Alliance Australia	info@geneticalliance.org.au	Telephone: +61 02 9295 8359	http://www.geneticalliance.org.au/
Australia	GARDN - Genetic and Rare Disease Network	hello@gardn.org.au	Telephone: 1300 770 995	https://gardn.org.au
Australia	Genetic Support Network of Victoria	info@gsnv.org.au	Telephone: (03) 8341 6315	https://www.gsnv.org.au/
Australia	Rare Voices Australia	info@rarevoices.com.au	Telephone: 0497 003 104	http://www.rarevoices.org.au/
Australia / New Zealand / APAC	Advocacy Beyond Borders	hello@advocacybeyondborders.com	Telephone: +61 407 091 857	www.advocacybeyondborders.com
Austria	SMA Österreich (SMA Austria)	office@smaoesterreich.at		https://www.smaoesterreich.at/ & https://www.facebook.com/smaoesterreich
Bangladesh	Cure SMA Bangladesh	info@curesmabangladesh.org	Telephone: 88 0184 111 84 86	https://curesmabangladesh.org/ & https://www.facebook.com/CureSMABangladesh
Belarus	Belarusian Association of Assistance to Children and Young People with Disabilities	info@belapdi.org	Telephone: (017) 320 03 88	https://www.linkedin.com/company/association-of-assistance-to-children-and-young-people-with-disabilities/about/
Belgium	ABMM - Belgian Association Against Neuromuscular Diseases	info@abmm.be & secretariat@abmm.be		https://www.telethon.be/
Belgium	Spierziekten Vlaanderen (Belgian Association for Neuromuscular Diseases)	https://spierziektenvlaanderen.be/aanvraag-informatie/	Telephone: 32484462241	https://spierziektenvlaanderen.be/
Belgium	RADIOORG - Rare Diseases Organization Belgium	info@radiorg.be	Telephone: 32478727703	http://www.radiorg.be/
Bhutan	SMA Bhutan	smabhutangroup@gmail.com	Telephone: 97517551335	https://m.facebook.com/SMABHUTAN/
Bolivia	FAME Bolivia - Familias de Atrofia Muscular Espinal (Families of SMA)			https://www.facebook.com/Familia-AME-Bolivia-437207206701100/
Botswana	BORDIS - Botswana Organisation for Rare Diseases	rareconnectbotswana@gmail.com	Telephone: 267 74 182 601 & 267 71692565	https://www.facebook.com/Bordis.bw/
Brazil	INAME - Instituto Nacional da Atrofia Muscular Espinhal (National Institute of SMA)	contato@iname.org.br	Telephone: (11) 97982-7636	www.iname.org.br & https://www.facebook.com/institutoiname/
Brazil	ABRAME - Associação Brasileira de AME (SMA Association)		Telephone: (85) 9913.9057	https://www.abramebrasil.com.br/ & https://www.facebook.com/@abrameamebrasil/?locale=pt_BR
Brazil	Instituto Viva Iris	contato@vivairis.com.br	Telephone: (34) 99889-5538	www.vivairis.com
Brazil	Instituto de Luta Contra a AME Gianlucca Trevellin	https://gianluccaheroicontraame.com.br/contato/		https://gianluccaheroicontraame.com.br/
Brazil	Instituto PROCLAME (Proclame Institute for People with SMA)	contato@proclame.org.br		https://www.instagram.com/proclame.instituto/
Brazil	AAME - Amigos de Atrofia Muscular Espinhal (Friends of SMA)			https://www.facebook.com/AtrofiaMuscularEspinhal/?locale=pt_BR
Brazil	FEBER - Associação Brasileira de Enfermedades Raras (Brazilian Association of Rare Diseases)	feber_raras@hotmail.com	Telephone: (11) 94033-1348	https://feberraras.wixsite.com/feber-raras/enfermidades-raras
Brazil	Instituto Vidas Raras (Rare Lives Institute)	viveraras@vidararas.org.br	Telephone: (11) 2414-3060	http://www.vidasraras.org.br
Brazil	DONEM	contato@donem.com.br & suhellenbalbino@gmail.com	Telephone: (81) 99928-2766	https://www.facebook.com/p/DONEM-Associacao-C3%A7%C3%A3o-de-Amigos-e-Portadores-de-Doen%C3%A7as-Neuromusculares-100064684269453/?paipv=0&eav=Afag8-OpB7IArOUJnyhbHloj-8hN5bSijMRM9AQH2j-ZLylivbVdMwNNOj8_11eg&_rdr
Brazil	Instituto Fernando Lopes		Telephone: (43) 99119-9104	https://universocoletivoame.com.br/
Bulgaria	CMA България (SMA Bulgaria)	smabulgaria@abv.bg	Telephone: 0889 44 77 34	https://www.facebook.com/smabulgaria/?ref=page_internal
Bulgaria	NAPRD - National Alliance of People with Rare Diseases	tomov@raredis.org	Telephone: 359 88 832 3748	http://www.rare-bg.com/
Canada	Cure SMA Canada	sma_can@telus.net & fsmacan@telus.net	Telephone: (855) 824-1277 (toll free) & (604) 824-1277 & (604) 824-1363 (fax)	http://www.curesma.ca/
Canada	Canadian Organization for Rare Disorders	info@raredisorders.ca	Telephone: (416) 969-7464 & 1-877-302-7273	http://www.raredisorders.ca
Canada	Rare Disease Foundation	info@rarediseasefoundation.org & families@rarediseasefoundation.org	Telephone: (866) 348-6677	https://rarediseasefoundation.org/
Chile	FAME Chile - Familias de Atrofia Muscular Espinal (Families of SMA)	fame@famechile.cl	Telephone: +56 9 7278 9425	https://famechile.cl/ & https://www.facebook.com/famechile
Chile	FECHER - Federación Chilena de Enfermedades Raras (Chilean Federation of Rare Diseases)	contacto@fecher.cl		http://fecher.cl/ & https://www.facebook.com/groups/comunidadfecher/
China	Meier Advocacy & Support Center for SMA	info@meier.org.cn	Telephone: 86 4006060749	www.meier.org.cn
China	Illness Challenge Foundation	btz@chinaicf.org	Telephone: 4000408772	http://www.chinaicf.org/
China	Chinese Organization for Rare Disorders	public@cord.org.cn	Telephone: 86 1083545711	https://www.cord.org.cn/

Colombia	FAME Colombia Sara & Sofia - Fundación AME (SMA Foundation)	organizacion@famecolombia.org	Telephone: +57 316 853-1503	https://famecolombia.org/
Colombia	Federación Colombiana de Enfermedades Raras (FECOER; Colombian Federation of Rare Diseases)	info@fecoer.org	Telephone: 3209445674	http://www.fecoer.org/
Colombia	Fundación FUPER	contacto@fundacionfuper.org	Telephone: +57 304 584 5121	http://www.fundacionfuper.org/
Costa Rica	FAME Costa Rica - Fundación AME (SMA Foundation)	fundacionamecr@gmail.com	Telephone: 71082515	https://www.facebook.com/FundaAtrofiaMuscularEspinal/
Cyprus	CARD - Cyprus Alliance for Rare Disorders	card@raredisorderscyprus.com	Telephone: 357 22 203762	http://raredisorderscyprus.com/
Cyprus	Pancyprian Association for Rare Genetic Diseases	info@monadikaxamogela.org	Telephone: 35799219079	http://www.monadikaxamogela.com/
Cyprus	MDA Cyprus	mda@cing.ac.cy	Telephone: 357 22392610	mdacyprus.org
Czech Republic	Project Supporting Families with SMA and Dystrophies	tuprovas@kolpingsmecno.cz & https://www.kolpingsmecno.cz/kontakt/		http://www.dumrodin.cz/
Czech Republic	Ceska Asociace Pro Vzacna Onemocneni (Rare Diseases Czech Republic)	cavo@vzacna-onemocneni.cz	Telephone: 420774 151290	http://www.vzacna-onemocneni.cz/
Czech Republic	SMÁČi	info@smaci.cz	Telephone: +420 731 510 663	http://www.smaci.cz/
Denmark	Danish National Rehabilitation Center for Neuromuscular Diseases (RCFM)	info@rcfm.dk	Telephone: +45 8948 2222	https://rcfm.dk/
Denmark	Muskelsvindfonden (Muscular Dystrophy Fund)	info@muskelsvindfonden.dk	Telephone: 89 48 22 22	https://muskelsvindfonden.dk/
Denmark	Sjældne Diagnoser (Rare Diseases Denmark)	mail@sjældnediagnoser.dk	Telephone: 4533140010	http://sjældnediagnoser.dk/rare-diseases/
Ecuador	FAME Ecuador - Fundación AME (SMA Foundation)	fameecuador@hotmail.com	Telephone: +593 97 908 7742	https://www.facebook.com/FamiliasAmEcuador/about/?ref=page_in_ternal
Egypt	Cure SMA Egypt	cure.sma.egypt@gmail.com		https://www.facebook.com/CureSMAegypt/ & http://www.curesmaegypt.org/
Estonia	The Estonian Association of Muscular Disorders	els@els.ee	Telephone: 526 0140	http://www.els.ee/index.php?page=42 & https://www.facebook.com/EestiLihashaigeteSelts
Europe	SMA Europe	secretariat@sma-europe.eu		http://www.sma-europe.eu/
Europe	EAMDA: European Alliance of Neuromuscular Disorders Association	secretariat@eamda.eu	Telephone: 38614720556	http://www.eamda.eu/
Europe	EURODIS: Rare Diseases Europe	eurordis@eurordis.org		http://www.eurordis.org/
Europe	Treat-NMD	info@treat-nmd.com		https://www.treat-nmd.org/
Finland	SMA Finland	hallitus@smafinland.fi		http://www.smafinland.fi/ & https://www.facebook.com/smafinland/
Finland	HARSO - Rare Disease Alliance Finland	toimisto@harso.fi	Telephone: 358 40 199 3582	https://www.harso.fi/en/home/
Finland	The Finnish Neuromuscular Disorders Association	lihastautiliitto@lihastautiliitto.fi	Telephone: 044 736 1030	http://www.lihastautiliitto.fi/fi/Etusivu & https://www.facebook.com/Lihastautiliitto/
France	Families SMA France	fsma.france@gmail.com		https://www.fsma.fr/
France	ECLAS - Ensemble Contre L'Amyotrophie Spinale de Type 1 (Together Against Spinal Muscular Atrophy Type 1)	contact@eclas.fr & eclas.ca2013@gmail.com	Telephone: +33 (0) 6 72 13 66 75	https://www.eclas.fr/
France	AFM-Téléthon		Telephone: 0 800 35 36 37	www.afm-telethon.fr
France	Alliance Maladies Rares	contact@opathiesrares.org	Telephone: 33156535343	http://www.alliance-maladies-rares.org/
France	Solidarité Handicap Autour des Maladies Rares (Disability Solidarity Around Rare Diseases)	contact@solhand.org		http://www.solhand-maladiesrares.org/
Georgia	Georgian Foundation for Genetic and Rare Diseases	grd.georgia@gmail.com	Telephone: 995599 294439	
Germany	Initiative – Forschung und Therapie fuer SMA Deutsche Gesellschaft fuer Muskelkranke (Research and Therapy for SMA)	info@initiative-sma.de	Telephone: 089 - 12 71 74 47	https://www.initiative-sma.de/
Germany	DMS - German Muscle Foundation and SMA Germany	info@sma-deutschland.de	Telephone: +49 7252 973663	https://www.muskelfstiftung.de/
Germany	Kindness for Kids	info@kindness-for-kids.de	Telephone: 498921568580	http://www.kindness-for-kids.de/
Germany	Rare Diseases Germany	Info@achse-online.de	Telephone: 4930330070826	https://www.achse-online.de/de/was_tut_ACHSE/tag_der_seltenen/index.php
Germany	German Society for Muscular Diseases (DGM)	info@dgm.org	Telephone: 07665 94470	www.dgm.org
Ghana	Rare Disease Ghana Initiative	info@rarediseaseghana.org & https://www.rarediseaseghana.org/contact	Telephone: 233552716011	http://rarediseaseghana.org/
Greece	Greek Alliance for Rare Diseases	info@rarediseasesgreece.gr	Telephone: 30 6943448509	https://rarediseasesgreece.com/
Greece	Muscular Dystrophy Association Hellas	info@mdahellas.gr	Telephone: +30 210 3616980-1	https://mdahellas.gr/
Hong Kong	Families of SMA Charitable Trust Hong Kong	info@fsma.org.hk	Telephone: 2811 1767	https://www.fsma.org.hk/
Hong Kong	HKARD - Hong Kong Alliance for Rare Diseases	info@hkard.org	Telephone: (852) 2708 9363	http://www.hkard.org/
Hungary	Hungarian SMA Association	kapcsolat@smainfo.hu		https://smainfo.hu/
Hungary	HUFERDIS - Rare Diseases Hungary / Hungarian Federation of People with Rare and Congenital Diseases		Telephone: +36 1 790 4532	http://www.rirosz.hu/
Iceland	FSMA Iceland	fsma@fsma.is		fsma.is
India	Cure SMA India Foundation	info@curesmaindia.org	Telephone: 91-124-420 0997	https://www.curesmaindia.org/
India	ORDI - Organization for Rare Diseases India	contactus@ordindia.in	Telephone: 91-998-013 3300 & 91-889-2555 000	https://ordindia.in/
India	Rare Diseases India - Foundation for Research on Rare Diseases and Disorders	contact@rarediseasesindia.org	Telephone: 91-917-631 7500	http://www.rarediseasesindia.org
Indonesia	SMA Indonesia	info@smaindonesia.org		https://www.facebook.com/smaindonesia.org & https://smaindonesia.org/
Indonesia	Indonesia Rare Disorders	ina.raredisorders@gmail.com	Telephone: +62 812-8596-3586	https://www.facebook.com/IdRareDisorders/
Indonesia	Indonesia Care for Rare Diseases	ic.for.rd@gmail.com		https://www.facebook.com/IndonesiaCAREforRAREdiseases/
Iran	Rare Disease Foundation of Iran	info@radoir.org & international@radoir.org	Telephone: +98 (21) 66572937 – 66572947	http://radoir.org/en/ & https://www.youtube.com/channel/UCPiDBWO7qjffuyMq9bSjxsw/featured
Ireland	SMA Ireland	info@smaireland.com		http://smaireland.com/
Ireland	Muscular Dystrophy Ireland	https://www.tfaforms.com/4915478	Telephone: +353 01 6236414	http://www.mdi.ie/

Ireland	Northern Ireland Rare Disease Partnership	hello@nirpd.org.uk & support@nirpd.org.uk & info@nirpd.org.uk		https://www.nirpd.org.uk/
Ireland	Rare Diseases Ireland	advocacy@rdi.ie		http://rdi.ie/
Israel	SMA Israel Family Association	sma.org.il@gmail.com	Telephone: 972 50 774 40 86	https://www.sma.org.il/
Italy	ASAMSI - Associazione per lo Studio delle Atrofie Muscolari Spinali Infantili (Association for the Study of Infant Spinal Muscular Atrophies)	info@asamsi.org	Telephone: 39 05 4666 5890	https://www.asamsi.org/
Italy	Famiglie SMA (Families of SMA)	segreteria@famigliesma.org	Telephone: 39 02 5656 8312	www.famigliesma.org
Italy	UNIAMO - Federazione Italia Malattie Rare (Italian Rare Disease Federation)	segreteria@uniamo.org	Telephone: 39 06 4404 773	http://www.uniamo.org/
Japan	Japan SMA Family Association / Network for SMA	smajimkyoku@sma-kazoku.net		https://www.sma-kazoku.net/
Japan	ASRID - Advocacy Service for Rare and Intractable Diseases	https://ws.formzu.net/fgen/S5213847/		https://asrid.org/en
Kenya	Rare Disease Kenya	ask@rarediseasekenya.org	Telephone: +254 701 025753	http://rarediseasekenya.org/
Kosovo	Rare Diseases Kosovo		Telephone: 38344196127	https://www.facebook.com/Shoqata-e-S%C3%ABmundjeve-t%C3%AB-Rralla-Kosov%C3%AB-2034022230042375/
Kuwait	Kuwait Association for Rare Diseases	https://www.rarediseasekuwait.org/contacts		https://www.rarediseasekuwait.org/
Latin America	ALAME - Alianza Latinoamericana AME (Latin American SMA Alliance)	contactame@amelatam.org	Telephone: +44 7533 768502	https://amelatam.org/?fbclid=IwAR32o7Tsz2b0T79mzaWSJlJnVOMC2jsEv15zRjnrVyTRRanBCNj4_EQw
Latin America	ALIBER - Latin American Alliance for Rare Diseases	direccion@aliber.org	Telephone: 34654365221	http://aliber.org/
Latin America	Fupaeh - Applied Psychology Foundation for people with Orphan Diseases	info@fupaeh.org	Telephone: +5491173671793	https://fupaeh.org/en/home/
Latvia	Latvian Alliance for Rare Diseases	alianse@retasslimibas.lv	Telephone +371 29 157 967	https://retasslimibas.lv/
Libya	Muscular Dystrophy Patients Association in Libya	muscular.dys.pts.org.in.libya@gmail.com & info@nmdf.ly	Telephone: 00218945829514, 00218926813267	https://www.facebook.com/share/1575CANQ32/?mibextid=wwXlfr
Lithuania	Sraunija (Lithuanian Association of Patients with Genetic Neuromuscular Diseases)		Telephone: +370 686 12510	http://sraunija.lt/
Luxembourg	ALAN - Rare Diseases Luxembourg	info@alan.lu	Telephone: +352 266 112 - 1	https://alan.lu/
Macedonia	Stop SMA Macedonia	contact@stopsma.mk & stopsma.mk@yahoo.com	Telephone: +389 75 422 821	http://www.stopsma.mk/
Macedonia	NARDM - National Alliance for Rare Diseases of Macedonia	retkibolesti@gmail.com	Telephone: +389 70 705 446	https://www.facebook.com/NARBMacedonija/
Malaysia	WeCareJourney - Malaysia	hello@wecarejourney.org	Telephone: 60 12 522 5232	https://wecarejourney.org/
Malaysia	Spinal Muscular Atrophy Malaysia Association	official@smamalaysia.org.my & spinalmuscularatrophy.malaysia@gmail.com	Telephone: 012 - 482 4242	https://www.smamalaysia.org.my/
Malaysia	Asia Pacific Alliance of Rare Disease Organisations	admin@apardo.org	Telephone: (65) 6337 1900	https://www.apardo.org/
Malaysia	Malaysian Rare Disorders Society	info@mrd.org.my	Telephone: 60019 7714543	http://www.mrd.org.my/
Malta	The National Alliance for Rare Diseases Support Malta	info@rarediseasesmalta.com	Telephone: (+356) 9991 2373	http://rarediseasesmalta.com/ & https://www.facebook.com/rarediseasesmalta/
Mexico	AMAME - Asociación Mexicana de Atrofia Muscular Espinal (SMA Association)	amameac@gmail.com	Telephone: 52 33 1241 6761	https://www.facebook.com/AMAME-Asociaci%C3%B3n-Mexicana-de-Atrofia-Muscular-Espinal-499801370774624/
Mexico	CUR AME - Fundación Atrofia Muscular Espinal México (SMA Foundation)	contacto@curame.org.mx	Telephone: 8126851328	https://www.curame.org.mx/ & https://www.facebook.com/curame.ac/
Mexico	Iniciativa Pensemos en Cebbras México	pensemosencebrasmexico@gmail.com		https://cebrasmexico.org.mx/ & https://www.facebook.com/people/Iniciativa-Pensemos-en-Cebbras-M%C3%A9xico/100064581856616/?paipv=0&eav=AFzY22ICUJZdwj6nwHLtEusH2TtiualuRt_x5bnSuPelI9NaK_Olv1_or7xaUvEdM&_rd_r
Mexico	Federación Mexicana de Enfermedades Raras (Mexican Federation of Rare Diseases)	info@femexer.org & femexer@gmail.com	Telephone: 527773 333732	http://www.femexer.org/
Montenegro	National Organization for Rare Diseases of Montenegro	nvorborbcg@gmail.com	Telephone: +382 (0) 69 438 617	http://rijetkebolesti.com/ & https://www.facebook.com/Nacionalna-organizacija-za-rijetke-bolesti-Crne-Gore-1786143551671853/
Morocco	Spinal Muscular Atrophy Association Morocco			https://www.facebook.com/AMAS.Maroc?mibextid=ZbWKwL
Netherlands	Prinses Beatrix Spierfonds	info@spierfonds.nl	Telephone: 070 - 3 607 607	www.prinsesbeatrixspierfonds.nl
Netherlands	VSN - Vereniging Spierziekten Nederland (Dutch Neuromuscular Disease Association)	mail@spierziekten.nl	Telephone: 035 548 04 80	www.vsn.nl & https://www.spierziekten.nl/
New Zealand	SMA New Zealand			https://www.facebook.com/groups/380288029432908/
New Zealand	Rare Disorders New Zealand	enquiries@raredisorders.org.nz	Telephone: 6443851119	https://raredisorders.org.nz/
New Zealand	Muscular Dystrophy Association of New Zealand	info@mda.org.nz	Telephone: 0800 800 337	https://www.mda.org.nz/
Nigeria	Foundation for Neuromuscular Support	neuromuscularnigeria@gmail.com	Telephone: 234 905 667 2111	https://muscular dystrophyng.wordpress.com/ & https://www.facebook.com/muscular dystrophyng/
Norway	SMA Norge	styret@smanorge.no		https://www.facebook.com/smanorge
Norway	FFM - Foreningen for Muskelsykes (The Association for Muscle Disease)	ffm@ffm.no	Telephone: +47 411 907 02	https://ffm.no/
Norway	FFO - Funksjonshemmedes Felleorganisasjon (Norwegian Federation of Organizations of Disabled People)	post@ffo.no	Telephone: 4781556940	http://www.ffa.no
Panama	Fundación de Niños SMA Panamá (Foundation for Children with SMA)	fundacionsmapanama@gmail.com	Telephone: +507 6349-1462	https://www.facebook.com/people/Fundaci%C3%B3n-SMA-Panam%C3%A1/100052098026809/ & https://fundacionsmapanama.com/
Paraguay	AFAME - Asociación de Familias con Atrofia Muscular Espinal Paraguay (Association of Families with SMA)		Telephone: 595981914653	https://www.facebook.com/afame.paraguay
Paraguay	Fundación CureAME Paraguay		Telephone: 595 982 918241	https://www.facebook.com/people/Cureame-Paraguay/100071931092141/?paipv=0&eav=AFzFekSI4YDQuN5RSWFk09zFXyTn2mGyuu2oppnRqX8sTfS1DRN9WJYpG1ryN6G3pzo&rd_rdr

Peru	FAME Perú - Familias con Atrofia Muscular Espinal Perú (Families with SMA)	familiameperu@gmail.com	Telephone: +51 934 105 732	https://www.facebook.com/FAMEPERU1/
Peru	Esperantra-COPEPOFRE (Peruvian Coalition for Rare Diseases)	patients@esperantra.org	Telephone: +51 1 765 6325	http://www.esperantra.org/
Peru	FEFER - Federación Peruana de Enfermedades Raras (Federation of Rare Diseases)	enfermedadesrarasperu@gmail.com	Telephone: +51 1 795 0304	https://feferperu.org/
Philippines	Stand for SMA Philippines	smaphilippinesgroup@gmail.com		https://www.facebook.com/standforsma/
Philippines	PSOD - Philippine Society for Orphan Disorders, Inc.	info@psod.org.ph	Telephone: (02) 661 8935	http://www.psod.org.ph/
Poland	Fundacja SMA Poland (SMA Foundation)	info@fsma.pl	Telephone: 22 350 02 02	https://www.fsma.pl/
Poland	Fundacja Pomocy Chorym na Zaniż Mięśni in Szczecin (Foundation to Help Muscular Disease)	biuro@miesnie.szczecin.pl	Telephone: 695 745 441	https://miesnie.szczecin.pl/
Portugal	ANAME - Associação Nacional da Atrofia Muscular Espinhal	anameportugal@gmail.com & anamepor@anameportugal.pt	Telephone: 912126161	https://www.facebook.com/anamept/ & https://anameportugal.pt/
Portugal	Associação Portuguesa de Doentes Neuromusculares (Portuguese Neuromuscular Association)	info@apn.pt		http://apn.pt/apn/
Romania	Asociatia SMACARE Romania (SMA Care Association)	smacare.romania@gmail.com		https://www.facebook.com/profile.php?id=100064267466594&paipv=0&eav=AfYadNVF6fZAjomjbxDPNhoZOppGuGFxQfXlaNM6z-r2vkAuxyfh7PvKb1wX9-dleRg
Romania	Asociatia Familia SMA (SMA Family Association)	contact@familiasma.com	Telephone: 0721 577 029	https://familiasma.ro/ & https://www.facebook.com/as.familiaSMA
Romania	Raul-Sebastian Association	asociatiaraulsebastian@gmail.com	Telephone: 0746.288.807	https://asociatiaraulsebastian.wordpress.com/contact/
Romania	Romanian National Alliance for Rare Diseases	http://www.bolirareromania.ro/contact	Telephone: 40260 610033	http://www.bolirareromania.ro/
Russia	SMA Family Foundation Russia	info@f-sma.ru	Telephone: 7 (495) 544-49-89	www.f-sma.ru & https://www.facebook.com/smafamiliyussia/
Serbia	SMA Srbija (SMA Serbia)	smasrbija@sma.org.rs & office@sma.org.rs		https://smasrbija.rs/en/support/ & https://www.facebook.com/smasrbija/
Serbia	NORBS - National Organization for Rare Diseases Serbia	office@norbs.rs & linijapomoci@norbs.rs	Telephone: 0800 333 103	https://norbs.rs/
Singapore	Muscular Dystrophy Association of Singapore	mdas@mdas.org.sg	Telephone: (65) 6259 6933	https://www.mdas.org.sg/
Slovakia	SMA Slovakia	info@sma-slovakia.sk	Telephone: 421 908 304 163	https://www.sma-slovakia.sk/
Slovakia	Slovak Alliance of Rare Diseases	office@sazch.sk		http://sazch.sk/ & https://www.facebook.com/SlovenskaAlianciaZriedkavychChorob
Slovenia	National Alliance of Rare Diseases of Slovenia		Telephone: 38631824865	
Slovenia	Društvo distrofikov Slovenije (Dystrophy Society of Slovenia)	info@drustvo-distrofikov.si	Telephone: (01) 47-20-500	http://www.drustvo-distrofikov.si/
South Africa	Cure SMA South Africa			https://www.facebook.com/sma.community.za
South Africa	Rare Diseases South Africa	hello@rarediseases.co.za & https://www.rarediseases.co.za/contact-us	Telephone: +27 10 594 3844	http://www.rarediseases.co.za/
Spain	FundAME (Spinal Muscular Atrophy Association)	organizacion@fundame.net	Telephone: 34 634238004	www.fundame.net
Spain	ASEM Catalunya - Associacio Catalana de Persones Amb Malalties Neuromusculares (Association of People with Neuromuscular Diseases)	info@asemcatalunya.com	Telephone: 932 74 49 83/619 39 47 42	http://asemcatalunya.com/
Spain	ASEM Federation (Spanish Federation of Neuromuscular Diseases)	info@asem-esp.org	Telephone: 606588291	http://www.asem-esp.org/
Spain	Association of Rare Diseases D'Genes	info@dgenes.es	Telephone: 34968420287	https://www.dgenes.es/
Spain	FEDER - Federacion Espanola de Enfermedades Raras (Spanish Federation of Rare Diseases)	https://www.enfermedades-raras.org/contacto	Telephone: 91 533 40 08	http://www.enfermedades-raras.org/
Sweden	NSMA - Nätverket för Spinal Muskelatrofi (Spinal Muscular Atrophy Network Sweden)	info@nsma.se		nsma.nu & https://www.facebook.com/nsma.sverige
Sweden	Sällsynta Diagnoser (Rare Diseases Sweden)	info@sallsyntadiagnoser.se	Telephone: 072-722 18 34	https://www.sallsyntadiagnoser.se/
Sweden	CSD - Centrum för Sällsynta Diagnoser i Samverkan (Center for Rare Diagnoses)	https://csdsamverkan.se/csdisverige/jukvardsregionalacentrumforsallsyntadiagnoser.4.5d8a5cd41793ff87c4e5835.html	Telephone: 46709645902	https://csdsamverkan.se/ & https://www.facebook.com/NFSD.se
Switzerland	SMA Schweiz (SMA Switzerland)	info@sma-schweiz.ch		www.sma-schweiz.ch
Switzerland	ASRIMM - Association Suisse Romande Intervenant contre les Maladies neuroMusculaires (Association Suisse Romande Intervening Against NeuroMuscular Diseases)	info@asrimm.ch	Telephone: 41 24 420 78 00	https://www.asrimm.ch/
Switzerland	ProRaris Alliance for Rare Diseases Switzerland	contact@proraris.ch	Telephone: 021 887 68 86	https://www.proraris.ch/
Taiwan	Become the Miracle Association	info@smabma.org	Telephone: 0902-380-591	www.smabma.org
Taiwan	Taiwan Association of Spinal Muscular Atrophy Families	taiwansma@gmail.com	Telephone: 07-201-0675	https://www.taiwansma.org.tw/?p=hjpl&hl=zh-tw & http://www.facebook.com/taiwansma/
Taiwan	Taiwan Foundation for Rare Disorders	tfrd@tfrd.org.tw	Telephone: 886-2-2521-0717	https://www.tfrd2.org.tw/tfrd_eng/
Tanzania	Support Bridge for Students with Disabilities (SBSD)	info@sbsd.or.tz	Telephone: +255 688 237 275	www.sbsd.or.tz
Thailand	Thai Rare Disease Foundation	thairaredisease.f@gmail.com	Telephone: 098-247-2520	http://thairdf.org/
Tunisia	Association Tunisienne d'Amyotrophie Spinale (SMA Association of Tunisia)	association.sma.tunisie@gmail.com	Telephone: 216 53 434 377	https://www.facebook.com/p/Association-Tunisienne-dAmyotrophie-Spinale-100082159113965/?paipv=0&eav=AfYQrdLQXujzIBC-f267-uYy5AxYakRuPDV3Ci0KGtdhMHwaINnJhPw5BHzP8OI_bM&rd
Turkey	SMA Benimle Yürü Derneği (SMA Walk With Me Association)	info@sby.org.tr & bilgi@sby.org.tr	Telephone: +90 (212) 812 53 53	https://smabenimleyuru.org.tr/iletisim/
Turkey	Türkiye SMA Vakfı (Turkey SMA Foundation)	info@sma.org.tr	Telephone: 0 507 206 74 24	http://www.sma.org.tr/

Turkey	KASDER - Türkiye Kas Hastalıkları Derneği (Neuromuscular Association of Turkey)	info@kasder.org.tr	Telephone: +90 212 663 86 86	https://www.kasder.org.tr/
Ukraine	CSMA - Children with SMA Foundation Ukraine	info@csma.org.ua	Telephone: 380503640673	www.csma.org.ua
United Arab Emirates	UAE Rare Disease Society	https://uaerds.ae/site/index.php/en/contact-us-page	Telephone: 0097143986777	https://uaerds.ae/site/index.php/en/
United Kingdom	Spinal Muscular Atrophy UK	office@smuk.org.uk	Telephone: 01789 267520	https://smuk.org.uk/
United Kingdom	Treat SMA UK	treatsma@treatsma.uk	Telephone: 0300 800 0202	https://www.treatsma.uk/ & https://www.facebook.com/groups/treatsma.uk
United Kingdom	Genetic Alliance UK	contactus@geneticalliance.org.uk	Telephone: +44 (0) 20 7831 0883	https://geneticalliance.org.uk/
United Kingdom	Rare Disease UK	info@raredisease.org.uk	Telephone: 0300 124 0441	https://www.raredisease.org.uk/
Uruguay	FAME Uruguay - Familias de Atrofia Muscular Espinal (Families of SMA)	fameuruguay@gmail.com	Telephone: +598 94 410 865	http://fameuruguay.blogspot.com/ & https://www.facebook.com/fameuruguay/?ref=search
Uruguay	ATUERU - Asociacion Todos Unidos Enfermedades Raras Uruguay (United Association of Rare Diseases)	contacto@atuero.org.uy	Telephone: +598 22001444	https://www.facebook.com/ATUERU/ & https://atuero.org.uy/
Uruguay	FUDI - Uruguayan Federation of Disability Institutions	ditecuruguay2002@gmail.com	Telephone: +598 - 99 757 971	https://ditecuruguay.org/
Venezuela	FAME Venezuela - Familias y Amigos de la Atrofia Muscular Espinal (Families of SMA)	venezuela@fame-fsma.org	Telephone: +58 412-7342554	https://www.facebook.com/FAMECurAME/
Vietnam	VORD - Vietnamese Organization for Rare Diseases	info@rarediseases.vn	Telephone: +84 92 837 3532 / +84 94 293 0510	rarediseases.vn

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