

## International SMA Patient Advocacy Organizations

Country / Region	Name	Email	Telephone	Website(s)
Africa	African Alliance for Rare Diseases	info@africa-rare.org	Telephone: +27 010 594 3844	<a href="http://www.africa-rare.org/">http://www.africa-rare.org/</a> & <a href="https://africa-rare.org/wp-content/uploads/2016/10/Terms-of-Reference-Africa-Rare.org_.pdf">https://africa-rare.org/wp-content/uploads/2016/10/Terms-of-Reference-Africa-Rare.org_.pdf</a>
Albania	Rare Diseases Association Albania	<a href="http://rda-al.com/en/contact/">http://rda-al.com/en/contact/</a>	Telephone: 355 69 720 3644	<a href="http://rda-al.com/en/">http://rda-al.com/en/</a>
Algeria	Shifa Association of NeuroMuscular Diseases	shifa@live.fr	Telephone: +213 773744620	<a href="http://shifadz.wix.com/asso">http://shifadz.wix.com/asso</a>
Algeria	Algerian Alliance Against Rare Diseases	aamrare@aol.com	Telephone: +213 773744620	<a href="http://aamrdz.wixsite.com/rare">http://aamrdz.wixsite.com/rare</a>
Argentina	FAME Argentina - Familias de Atrofia Muscular Espinal (Families of SMA)	fameargentina@gmail.com	Telephone: +54 9 (11) 2164-8107	<a href="http://www.fameargentina.com.ar/">http://www.fameargentina.com.ar/</a> & <a href="https://www.facebook.com/FAME-Argentina-216974078365467/?eid=ARD57tAy68GLwOI0o1SyT7EygnYLNSFNJI6QxXud3yNeP804pHJufWYXUFMujHeytGYTAK1pWf7jGjw">https://www.facebook.com/FAME-Argentina-216974078365467/?eid=ARD57tAy68GLwOI0o1SyT7EygnYLNSFNJI6QxXud3yNeP804pHJufWYXUFMujHeytGYTAK1pWf7jGjw</a>
Argentina	ALAPA - Alianza Argentina de Pacientes (Patient Alliance)	info@alianzapacientes.org	Telephone: 54 911 2266 3101	<a href="http://alianzapacientes.org/">http://alianzapacientes.org/</a> & <a href="https://www.facebook.com/somosalapa/">https://www.facebook.com/somosalapa/</a>
Argentina	FADEPOF - Federación Argentina de Enfermedades Poco Frecuentes (Argentina Federation for Rare Diseases)	info@fadepof.org.ar & <a href="https://fadepof.org.ar/contacto.php">https://fadepof.org.ar/contacto.php</a>	Telephone: +54 9 (11) 3 901-221	<a href="http://fadepof.org.ar/">http://fadepof.org.ar/</a>
Asia	SMA Asia	info@smaasia.org		
Australia	Spinal Muscular Atrophy Australia Inc.	reception@smaaustralia.org.au		<a href="https://smaaustralia.org.au/">https://smaaustralia.org.au/</a>
Australia	Australasian Neuromuscular Network	jointheANN@gmail.com		<a href="http://www.ann.org.au/">http://www.ann.org.au/</a>
Australia	Genetic Alliance Australia	info@geneticalliance.org.au	Telephone: +61 02 9295 8359	<a href="http://www.geneticalliance.org.au/">http://www.geneticalliance.org.au/</a>
Australia	GARDN - Genetic and Rare Disease Network	hello@gardn.org.au	Telephone: 1300 770 995	<a href="https://gardn.org.au">https://gardn.org.au</a>
Australia	Genetic Support Network of Victoria	info@gsnv.org.au	Telephone: (03) 8341 6315	<a href="https://www.gsnv.org.au/">https://www.gsnv.org.au/</a>

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
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/
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	RADIORG - 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)			<a href="https://www.facebook.com/AtrofiaMuscularEspinhal/?locale=pt_BR">https://www.facebook.com/AtrofiaMuscularEspinhal/?locale=pt_BR</a>
Brazil	FEBER - Associação Brasileira de Enfermedades Raras (Brazilian Association of Rare Diseases)	feber_raras@hotmail.com	Telephone: (11) 94033-1348	<a href="https://feberraras.wixsite.com/feber-raras/enfermidades-raras">https://feberraras.wixsite.com/feber-raras/enfermidades-raras</a>
Brazil	Instituto Vidas Raras (Rare Lives Institute)	viveraras@vidararas.org.br	Telephone: (11) 2414-3060	<a href="http://www.vidasraras.org.br">http://www.vidasraras.org.br</a>
Brazil	DONEM	contato@donem.com.br & suhellenbalbino@gmail.com	Telephone: (81) 99928-2766	<a href="https://www.facebook.com/Associa%C3%A7%C3%A3o-de-Amigos-e-Portadores-de-Doen%C3%A7as-Neuromusculares-100064684269453/?paipv=0&amp;eav=Afag8-OpB7IAriOUJnyhbHloj-8hN5bSijMRM9AQH2j-ZLyilvbVdMwNNOj8_l1eg&amp;_rdr">Associa%C3%A7%C3%A3o-de-Amigos-e-Portadores-de-Doen%C3%A7as-Neuromusculares-100064684269453/?paipv=0&amp;eav=Afag8-OpB7IAriOUJnyhbHloj-8hN5bSijMRM9AQH2j-ZLyilvbVdMwNNOj8_l1eg&amp;_rdr</a>
Brazil	Instituto Fernando Lopes		Telephone: (43) 99119-9104	<a href="https://universocoletivoame.com.br/">https://universocoletivoame.com.br/</a>
Bulgaria	СМА България (SMA Bulgaria)	smabulgaria@abv.bg	Telephone: 0889 44 77 34	<a href="https://www.facebook.com/smabulgaria/?ref=page_internal">https://www.facebook.com/smabulgaria/?ref=page_internal</a>
Bulgaria	NAPRD - National Alliance of People with Rare Diseases	tomov@raredis.org	Telephone: 359 88 832 3748	<a href="http://www.rare-bg.com/">http://www.rare-bg.com/</a>
Canada	Cure SMA Canada	sma_can@telus.net & fsmacan@telus.net	Telephone: (855) 824-1277 (toll free) & (604) 824-1277 & (604) 824-1363 (fax)	<a href="http://www.curesma.ca/">http://www.curesma.ca/</a>
Canada	Canadian Organization for Rare Disorders	info@raredisorders.ca	Telephone: (416) 969-7464 & 1-877-302-7273	<a href="http://www.raredisorders.ca">http://www.raredisorders.ca</a>
Canada	Rare Disease Foundation	info@rarediseasefoundation.org & families@rarediseasefoundation.org	Telephone: (866) 348-6677	<a href="https://rarediseasefoundation.org/">https://rarediseasefoundation.org/</a>
Chile	FAME Chile - Familias de Atrofia Muscular Espinal (Families of SMA)	fame@famechile.cl	Telephone: +56 9 7278 9425	<a href="https://famechile.cl/">https://famechile.cl/</a> & <a href="https://www.facebook.com/famechile">https://www.facebook.com/famechile</a>
Chile	FECHER - Federación Chilena de Enfermedades Raras (Chilean Federation of Rare Diseases)	contacto@fecher.cl		<a href="http://fecher.cl/">http://fecher.cl/</a> & <a href="https://www.facebook.com/groups/comunidadfecher/">https://www.facebook.com/groups/comunidadfecher/</a>
Chile	Fundación Todos Somos Amanda	fundaciontodossomosamanda@gmail.com	Telephone: +56988166943	<a href="http://www.fundaciontodossomosamanda.cl">www.fundaciontodossomosamanda.cl</a>
China	Meier Advocacy & Support Center for SMA	info@meier.org.cn	Telephone: 86 4006060749	<a href="http://www.meier.org.cn">www.meier.org.cn</a>

China	Illness Challenge Foundation	bttz@chinaicf.org	Telephone: 4000408772	<a href="http://www.chinaicf.org/">http://www.chinaicf.org/</a>
China	Chinese Organization for Rare Disorders	public@cord.org.cn	Telephone: 86 1083545711	<a href="https://www.cord.org.cn/">https://www.cord.org.cn/</a>
Colombia	FAME Colombia Sara & Sofia - Fundación AME (SMA Foundation)	organizacion@famecolombia.org	Telephone: +57 316 853-1503	<a href="https://famecolombia.org/">https://famecolombia.org/</a>
Colombia	Federación Colombiana de Enfermedades Raras (FECOER; Colombian Federation of Rare Diseases)	info@fecoer.org	Telephone: 3209445674	<a href="http://www.fecoer.org/">http://www.fecoer.org/</a>
Colombia	Fundacion FUPER	contacto@fundacionfuper.org	Telephone: +57 304 584 5121	<a href="http://www.fundacionfuper.org/">http://www.fundacionfuper.org/</a>
Costa Rica	FAME Costa Rica - Fundación AME (SMA Foundation)	fundacionamecr@gmail.com	Telephone: 71082515	<a href="https://www.facebook.com/FundaAtrofiaMuscularEspinal/">https://www.facebook.com/FundaAtrofiaMuscularEspinal/</a>
Cyprus	CARD - Cyprus Alliance for Rare Disorders	card@raredisorderscyprus.com	Telephone: 357 22 203762	<a href="http://raredisorderscyprus.com/">http://raredisorderscyprus.com/</a>
Cyprus	Pancyprian Association for Rare Genetic Diseases	info@monadikaxamogela.org	Telephone: 35799219079	<a href="http://www.monadikaxamogela.com/">http://www.monadikaxamogela.com/</a>
Cyprus	MDA Cyprus	mda@cing.ac.cy	Telephone: 357 22392610	mdacyprus.org
Czech Republic	Project Supporting Families with SMA and Dystrophies	tuprovas@kolpingsmecno.cz & <a href="https://www.kolpingsmecno.cz/kontakt/">https://www.kolpingsmecno.cz/kontakt/</a>		<a href="http://www.dumrodin.cz/">http://www.dumrodin.cz/</a>
Czech Republic	Ceska Asociace Pro Vzacna Onemocneni (Rare Diseases Czech Republic)	cavo@vzacna-onemocneni.cz	Telephone: 420774 151290	<a href="http://www.vzacna-onemocneni.cz/">http://www.vzacna-onemocneni.cz/</a>
Czech Republic	SMÁci	info@smaci.cz	Telephone: +420 731 510 663	<a href="http://www.smaci.cz/">http://www.smaci.cz/</a>
Denmark	Danish National Rehabilitation Center for Neuromuscular Diseases (RCFM)	info@rcfm.dk	Telephone: +45 8948 2222	<a href="https://rcfm.dk/">https://rcfm.dk/</a>
Denmark	Muskelsvindfonden (Muscular Dystrophy Fund)	info@muskelsvindfonden.dk	Telephone: 89 48 22 22	<a href="https://muskelsvindfonden.dk/">https://muskelsvindfonden.dk/</a>
Denmark	Sjaeldne Diagnoser (Rare Diseases Denmark)	mail@sjaldnediagnoser.dk	Telephone: 4533140010	<a href="http://sjaldnediagnoser.dk/rare-diseases/">http://sjaldnediagnoser.dk/rare-diseases/</a>
Ecuador	FAME Ecuador - Fundación AME (SMA Foundation)	fameecuador@hotmail.com	Telephone: +593 97 908 7742	<a href="https://www.facebook.com/FamiliasAmeEcuador/about/?ref=page_internal">https://www.facebook.com/FamiliasAmeEcuador/about/?ref=page_internal</a>

Egypt	Cure SMA Egypt	cure.sma.egypt@gmail.com		<a href="https://www.facebook.com/CureSMAegypt/">https://www.facebook.com/CureSMAegypt/</a> & <a href="http://www.curesmaegypt.org/">http://www.curesmaegypt.org/</a>
Estonia	The Estonian Association of Muscular Disorders	els@els.ee	Telephone: 526 0140	<a href="http://www.els.ee/index.php?page=42">http://www.els.ee/index.php?page=42</a> & <a href="https://www.facebook.com/EestiLihasehaigeteSelts">https://www.facebook.com/EestiLihasehaigeteSelts</a>
Europe	SMA Europe	secretariat@sma-europe.eu		<a href="http://www.sma-europe.eu/">http://www.sma-europe.eu/</a>
Europe	EAMDA: European Alliance of Neuromuscular Disorders Association	secretariat@eamda.eu	Telephone: 38614720556	<a href="http://www.eamda.eu/">http://www.eamda.eu/</a>
Europe	EURODIS: Rare Diseases Europe	eurordis@eurordis.org		<a href="http://www.eurordis.org/">http://www.eurordis.org/</a>
Europe	Treat-NMD	info@treat-nmd.com		<a href="https://www.treat-nmd.org/">https://www.treat-nmd.org/</a>
Finland	SMA Finland	hallitus@smafinland.fi		<a href="http://www.smafinland.fi/">http://www.smafinland.fi/</a> & <a href="https://www.facebook.com/smafinland/">https://www.facebook.com/smafinland/</a>
Finland	HARSO - Rare Disease Alliance Finland	toimisto@harso.fi	Telephone: 358 40 199 3582	<a href="https://www.harso.fi/en/home/">https://www.harso.fi/en/home/</a>
Finland	The Finnish Neuromuscular Disorders Association	lihastautiliitto@lihastautiliitto.fi	Telephone: 044 736 1030	<a href="http://www.lihastautiliitto.fi/fi/Etusivu">http://www.lihastautiliitto.fi/fi/Etusivu</a> & <a href="https://www.facebook.com/Lihastautiliitto/">https://www.facebook.com/Lihastautiliitto/</a>
France	Families SMA France	fsma.france@gmail.com		<a href="https://www.fsma.fr/">https://www.fsma.fr/</a>
France	ECLAS - Ensemble Contre L'Amyotrophie Spinale de Type 1 (Together Against Spinal Muscular Atrophy Type 1)	contact@eclas.fr & <a href="mailto:eclas.ca2013@gmail.com">eclas.ca2013@gmail.com</a>	Telephone: +33 (0) 6 72 13 66 75	<a href="https://www.eclas.fr/">https://www.eclas.fr/</a>
France	AFM-Téléthon		Telephone: 0 800 35 36 37	<a href="http://www.afm-telethon.fr">www.afm-telethon.fr</a>
France	Alliance Maladies Rares	contact@opathiesrares.org	Telephone: 33156535343	<a href="http://www.alliance-maladies-rares.org/">http://www.alliance-maladies-rares.org/</a>
France	Solidarité Handicap Autour des Maladies Rares (Disability Solidarity Around Rare Diseases)	contact@solhand.org		<a href="http://www.solhand-maladiesrares.org/">http://www.solhand-maladiesrares.org/</a>
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 Muskelranke (Research and Therapy for SMA)	info@initiative-sma.de	Telephone: 089 - 12 71 74 47	<a href="https://www.initiative-sma.de/">https://www.initiative-sma.de/</a>
Germany	DMS - German Muscle Foundation and SMA Germany	info@sma-deutschland.de	Telephone: +49 7252 973663	<a href="https://www.muskelstiftung.de/">https://www.muskelstiftung.de/</a>
Germany	Kindness for Kids	info@kindness-for-kids.de	Telephone: 498921568580	<a href="http://www.kindness-for-kids.de/">http://www.kindness-for-kids.de/</a>
Germany	Rare Diseases Germany	Info@achse-online.de	Telephone: 4930330070826	<a href="https://www.achse-online.de/de/was_tut_ACHSE/tag_der_seltenen/index.php">https://www.achse-online.de/de/was_tut_ACHSE/tag_der_seltenen/index.php</a>
Germany	German Society for Muscular Diseases (DGM)	info@dgm.org	Telephone: 07665 94470	<a href="http://www.dgm.org">www.dgm.org</a>
Ghana	Rare Disease Ghana Initiative	info@rarediseaseghana.org & <a href="https://www.rarediseaseghana.org/contact">https://www.rarediseaseghana.org/contact</a>	Telephone: 233552716011	<a href="http://rarediseaseghana.org/">http://rarediseaseghana.org/</a>
Greece	Greek Alliance for Rare Diseases	info@rarediseasesgreece.gr	Telephone: 30 6943448509	<a href="https://rarediseasesgreece.com/">https://rarediseasesgreece.com/</a>
Greece	Muscular Dystrophy Association Hellas	info@mdahellas.gr	Telephone: +30 210 3616980-1	<a href="https://mdahellas.gr/">https://mdahellas.gr/</a>
Hong Kong	Families of SMA Charitable Trust Hong Kong	info@fsma.org.hk	Telephone: 2811 1767	<a href="https://www.fsma.org.hk/">https://www.fsma.org.hk/</a>
Hong Kong	HKARD - Hong Kong Alliance for Rare Diseases	info@hkard.org	Telephone: (852) 2708 9363	<a href="http://www.hkard.org/">http://www.hkard.org/</a>
Hungary	Hungarian SMA Association	kapcsolat@smainfo.hu		<a href="https://smainfo.hu/">https://smainfo.hu/</a>
Hungary	HUFERDIS - Rare Diseases Hungary / Hungarian Federation of People with Rare and Congenital Diseases		Telephone: +36 1 790 4532	<a href="http://www.rirosz.hu/">http://www.rirosz.hu/</a>
Iceland	FSMA Iceland	fsma@fsma.is		<a href="http://fsma.is">fsma.is</a>
India	Cure SMA India Foundation	info@curesmaindia.org	Telephone: 91-124-420 0997	<a href="https://www.curesmaindia.org/">https://www.curesmaindia.org/</a>
India	ORDI - Organization for Rare Diseases India	contactus@ordindia.in	Telephone: 91-998-013 3300 & 91-889-2555 000 ☐	<a href="https://ordindia.in/">https://ordindia.in/</a>

India	Rare Diseases India - Foundation for Research on Rare Diseases and Disorders	contact@rarediseasesindia.org	Telephone: 91-917-631 7500	<a href="http://www.rarediseasesindia.org">http://www.rarediseasesindia.org</a>
Indonesia	SMA Indonesia	info@smaindonesia.org		<a href="https://www.facebook.com/smaindonesia.org">https://www.facebook.com/smaindonesia.org</a> & <a href="https://smaindonesia.org/">https://smaindonesia.org/</a>
Indonesia	Indonesia Rare Disorders	ina.raredisorders@gmail.com	Telephone: +62 812-8596-3586	<a href="https://www.facebook.com/IdRareDisorders/">https://www.facebook.com/IdRareDisorders/</a>
Indonesia	Indonesia Care for Rare Diseases	ic.for.rd@gmail.com		<a href="https://www.facebook.com/IndonesiaCAREforRAREDiseases/">https://www.facebook.com/IndonesiaCAREforRAREDiseases/</a>
Iran	Rare Disease Foundation of Iran	info@radoir.org & international@radoir.org	Telephone: +98 (21) 66572937 – 66572947	<a href="http://radoir.org/en/">http://radoir.org/en/</a> & <a href="https://www.youtube.com/channel/UCPiDBW07qjffuyMq9bSjxsw/featured">https://www.youtube.com/channel/UCPiDBW07qjffuyMq9bSjxsw/featured</a>
Iraq	Al Mujib Organization		Telephone: +9647716282143	<a href="https://www.facebook.com/profile.php?id=100072141323944&amp;mibextid=wwXlfr&amp;rdid=zwUaD0f5OaU6XbrT#">https://www.facebook.com/profile.php?id=100072141323944&amp;mibextid=wwXlfr&amp;rdid=zwUaD0f5OaU6XbrT#</a>
Ireland	SMA Ireland	info@smaireland.com		<a href="http://smaireland.com/">http://smaireland.com/</a>
Ireland	Muscular Dystrophy Ireland	<a href="https://www.tfaforms.com/4915478">https://www.tfaforms.com/4915478</a>	Telephone: +353 01 6236414	<a href="http://www.mdi.ie/">http://www.mdi.ie/</a>
Ireland	Northern Ireland Rare Disease Partnership	hello@nirpd.org.uk & support@nirdp.org.uk & info@nirdp.org.uk		<a href="https://www.nirdp.org.uk/">https://www.nirdp.org.uk/</a>
Ireland	Rare Diseases Ireland	advocacy@rdi.ie		<a href="http://rdi.ie/">http://rdi.ie/</a>
Israel	SMA Israel Family Association	sma.org.il@gmail.com	Telephone: 972 50 774 40 86	<a href="https://www.sma.org.il/">https://www.sma.org.il/</a>
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	<a href="https://www.asamsi.org/">https://www.asamsi.org/</a>
Italy	Famiglie SMA (Families of SMA)	segreteria@famigliesma.org	Telephone: 39 02 5656 8312	<a href="http://www.famigliesma.org">www.famigliesma.org</a>
Italy	UNIAMO - Federazione Italia Malattie Rare (Italian Rare Disease Federation)	segreteria@uniamo.org	Telephone: 39 06 4404 773	<a href="http://www.uniamo.org/">http://www.uniamo.org/</a>
Japan	Japan SMA Family Association / Network for SMA	smajimkyoku@sma-kazoku.net		<a href="https://www.sma-kazoku.net/">https://www.sma-kazoku.net/</a>

Japan	ASRID - Advocacy Service for Rare and Intractable Diseases	<a href="https://ws.formzu.net/fgen/S5213847/">https://ws.formzu.net/fgen/S5213847/</a>		<a href="https://asrid.org/en">https://asrid.org/en</a>
Kenya	Rare Disease Kenya	<a href="mailto:ask@rarediseasekenya.org">ask@rarediseasekenya.org</a>	Telephone: +254 701 025753	<a href="http://rarediseasekenya.org/">http://rarediseasekenya.org/</a>
Kosovo	Rare Diseases Kosovo		Telephone: 38344196127	<a href="https://www.facebook.com/Shoqata-e-S%C3%ABmundjeve-t%C3%AB-Rralla-Kosov%C3%AB-2034022230042375/">https://www.facebook.com/Shoqata-e-S%C3%ABmundjeve-t%C3%AB-Rralla-Kosov%C3%AB-2034022230042375/</a>
Kuwait	Kuwait Association for Rare Diseases	<a href="https://www.rarediseasekuwait.org/contacts">https://www.rarediseasekuwait.org/contacts</a>		<a href="https://www.rarediseasekuwait.org/">https://www.rarediseasekuwait.org/</a>
Latin America	ALAME - Alianza Latinoamerica AME (Latin American SMA Alliance)	<a href="mailto:contactame@amelatam.org">contactame@amelatam.org</a>	Telephone: +44 7533 768502	<a href="https://amelatam.org/?fbclid=IwAR32o7Tsz2b0T79mzaWSJlJnWVOMC2jsEv115zRjnrVyTRRanBCNJ4_EQw">https://amelatam.org/?fbclid=IwAR32o7Tsz2b0T79mzaWSJlJnWVOMC2jsEv115zRjnrVyTRRanBCNJ4_EQw</a>
Latin America	ALIBER - Latin American Alliance for Rare Diseases	<a href="mailto:direccion@aliber.org">direccion@aliber.org</a>	Telephone: 34654365221	<a href="http://aliber.org/">http://aliber.org/</a>
Latvia	Latvian Alliance for Rare Diseases	<a href="mailto:alianse@retasslimibas.lv">alianse@retasslimibas.lv</a>	Telephone +371 29 157 967	<a href="https://retasslimibas.lv/">https://retasslimibas.lv/</a>
Libya	Muscular Dystrophy Patients Association in Libya	<a href="mailto:muscular.dys.pts.org.in.libya@gmail.com">muscular.dys.pts.org.in.libya@gmail.com</a> & <a href="mailto:info@nmdf.ly">info@nmdf.ly</a>	Telephone: 00218945829514, 00218926813267	<a href="https://www.facebook.com/share/1575CAnQ32/?mibextid=wwXlfr">https://www.facebook.com/share/1575CAnQ32/?mibextid=wwXlfr</a>
Lithuania	Sraunija (Lithuanian Association of Patients with Genetic Neuromuscular Diseases)		Telephone: +370 686 12510	<a href="http://sraunija.lt/">http://sraunija.lt/</a>
Luxembourg	ALAN - Rare Diseases Luxembourg	<a href="mailto:infolineMR@alan.lu">infolineMR@alan.lu</a>	Telephone: +352 266 112 - 1	<a href="https://alan.lu/">https://alan.lu/</a>
Macedonia	Stop SMA Macedonia	<a href="mailto:contact@stopsma.mk">contact@stopsma.mk</a> & <a href="mailto:stopsma.mk@yahoo.com">stopsma.mk@yahoo.com</a>	Telephone: +389 75 422 821	<a href="http://www.stopsma.mk/">http://www.stopsma.mk/</a>
Macedonia	NARDM - National Alliance for Rare Diseases of Macedonia	<a href="mailto:retkibolesti@gmail.com">retkibolesti@gmail.com</a>	Telephone: +389 70 705 446	<a href="https://www.facebook.com/NARBMakedonija/">https://www.facebook.com/NARBMakedonija/</a>
Malaysia	WeCareJourney – Malaysia	<a href="mailto:hello@wecarejourney.org">hello@wecarejourney.org</a>	Telephone: 60 12 522 5232	<a href="https://wecarejourney.org/">https://wecarejourney.org/</a>
Malaysia	Spinal Muscular Atrophy Malaysia Association	<a href="mailto:official@smamalaysia.org.my">official@smamalaysia.org.my</a> & <a href="mailto:spinalmuscularatrophy.malaysia@gmail.com">spinalmuscularatrophy.malaysia@gmail.com</a>	Telephone: 012 - 482 4242	<a href="https://www.smamalaysia.org.my/">https://www.smamalaysia.org.my/</a>
Malaysia	Asia Pacific Alliance of Rare Disease Organisations	<a href="mailto:admin@apardo.org">admin@apardo.org</a>	Telephone: (65) 6337 1900	<a href="https://www.apardo.org/">https://www.apardo.org/</a>

Malaysia	Malaysian Rare Disorders Society	info@mrds.org.my	Telephone: 60019 7714543	<a href="http://www.mrds.org.my/">http://www.mrds.org.my/</a>
Malta	The National Alliance for Rare Diseases Support Malta	info@rarediseasesmalta.com	Telephone: (+356) 9991 2373	<a href="http://rarediseasesmalta.com/">http://rarediseasesmalta.com/</a> & <a href="https://www.facebook.com/rarediseasesmalta/">https://www.facebook.com/rarediseasesmalta/</a>
Mexico	AMAME - Asociación Mexicana de Atrofia Muscular Espinal (SMA Association)	amameac@gmail.com	Telephone: 52 33 1241 6761	<a href="https://www.facebook.com/AMAME-Asociaci%C3%B3n-Mexicana-de-Atrofia-Muscular-Espinal-499801370774624/">https://www.facebook.com/AMAME-Asociaci%C3%B3n-Mexicana-de-Atrofia-Muscular-Espinal-499801370774624/</a>
Mexico	CUR AME - Fundación Atrofia Muscular Espinal México (SMA Foundation)	contacto@curame.org.mx	Telephone: 8126851328	<a href="https://www.curame.org.mx/">https://www.curame.org.mx/</a> & <a href="https://www.facebook.com/curame.ac/">https://www.facebook.com/curame.ac/</a>
Mexico	Iniciativa Pensemos en Cebras México	pensemosencebrasmexico@gmail.com		<a href="https://cebrasmexico.org.mx/">https://cebrasmexico.org.mx/</a> & <a href="https://www.facebook.com/people/Iniciativa-Pensemos-en-Cebras-M%C3%A9xico/100064581856616/?paipv=0&amp;ea v=AfZYZ2ICUjZdwj6nwHLEusH2TtiualuRt_x5bnSuPeli9NaK_Olv1_or7xaUVoEdM&amp;_rdr">https://www.facebook.com/people/Iniciativa-Pensemos-en-Cebras-M%C3%A9xico/100064581856616/?paipv=0&amp;ea v=AfZYZ2ICUjZdwj6nwHLEusH2TtiualuRt_x5bnSuPeli9NaK_Olv1_or7xaUVoEdM&amp;_rdr</a>
Mexico	Federación Mexicana de Enfermedades Raras (Mexican Federation of Rare Diseases)	info@femexer.org & femexer@gmail.com	Telephone: 527773 333732	<a href="http://www.femexer.org/">http://www.femexer.org/</a>
Montenegro	National Organization for Rare Diseases of Montenegro	nvonorbcbg@gmail.com	Telephone: +382 (0 ) 69 438 617	<a href="http://rijetkebolesti.com/">http://rijetkebolesti.com/</a> & <a href="https://www.facebook.com/Nacionalna-organizacija-za-rijetke-bolesti-Crne-Gore-1786143551671853/">https://www.facebook.com/Nacionalna-organizacija-za-rijetke-bolesti-Crne-Gore-1786143551671853/</a>
Morocco	Spinal Muscular Atrophy Association Morocco			<a href="https://www.facebook.com/AMAS.Maroc?mibextid=ZbWKwL">https://www.facebook.com/AMAS.Maroc?mibextid=ZbWKwL</a>
Netherlands	Prinses Beatrix Spierfonds	info@spierfonds.nl	Telephone: 070 - 3 607 607	<a href="http://www.prinsesbeatrixspierfonds.nl">www.prinsesbeatrixspierfonds.nl</a>
Netherlands	VSN - Vereniging Spierziekten Nederland (Dutch Neuromuscular Disease Association)	mail@spierziekten.nl	Telephone: 035 548 04 80	<a href="http://www.vsn.nl">www.vsn.nl</a> & <a href="https://www.spierziekten.nl/">https://www.spierziekten.nl/</a>
New Zealand	SMA New Zealand			<a href="http://www.sma.org.nz/">http://www.sma.org.nz/</a>
New Zealand	Rare Disorders New Zealand	enquiries@raredisorders.org.nz	Telephone: 6443851119	<a href="https://raredisorders.org.nz/">https://raredisorders.org.nz/</a>

New Zealand	Muscular Dystrophy Association of New Zealand	info@mda.org.nz	Telephone: 0800 800 337	<a href="https://www.mda.org.nz/">https://www.mda.org.nz/</a>
Nigeria	Foundation for Neuromuscular Support	neuromuscularnigeria@gmail.com	Telephone: 234 905 667 2111	<a href="https://muscular dystrophyng.wordpress.com/">https://muscular dystrophyng.wordpress.com/</a> & <a href="https://www.facebook.com/muscular dystrophyng/">https://www.facebook.com/muscular dystrophyng/</a>
Norway	SMA Norge	styret@smanorge.no		<a href="https://www.facebook.com/smanorge">https://www.facebook.com/smanorge</a>
Norway	FFM - Foreningen for Muskelsykes (The Association for Muscle Disease)	ffm@ffm.no	Telephone: +47 411 907 02	<a href="https://ffm.no/">https://ffm.no/</a>
Norway	FFO - Funksjonshemmedes Felleorganisasjon (Norwegian Federation of Organizations of Disabled People)	post@ffo.no	Telephone: 4781556940	<a href="http://www.ffe.no">http://www.ffe.no</a>
Pakistan	Strive Eradication of Disability Foundation (Strive Foundation)	info@strivefoundation.co	Telephone: +92 304 111 5811	<a href="https://strivefoundation.co/">https://strivefoundation.co/</a>
Palestine	SMA Palestine	contact@sma-palestine.org		<a href="http://www.sma-palestine.org">www.sma-palestine.org</a>
Panama	Fundación de Niños SMA Panamá (Foundation for Children with SMA)	fundacionsmapanama@gmail.com	Telephone: +507 6349-1462	<a href="https://www.facebook.com/people/Fundaci%C3%B3n-SMA-Panam%C3%A1/100052098026809/">https://www.facebook.com/people/Fundaci%C3%B3n-SMA-Panam%C3%A1/100052098026809/</a> & <a href="https://fundacionsmapanama.com/">https://fundacionsmapanama.com/</a>
Paraguay	AFAME - Asociación de Familias con Atrofia Muscular Espinal Paraguay (Association of Families with SMA)		Telephone: 595981914653	<a href="https://www.facebook.com/afame.paraguay">https://www.facebook.com/afame.paraguay</a>
Paraguay	Fundación CureAME Paraguay		Telephone: 595 982 918241	<a href="https://www.facebook.com/people/Curame-Paraguay/100071931092141/?paipv=0&amp;eav=AfZFekSI4YDQuN5RSWFk09zfXYtN2mGYuu2oppnRqX8sTfs1DRN9WJYpG1ryN6G3pzo&amp;_rdr">https://www.facebook.com/people/Curame-Paraguay/100071931092141/?paipv=0&amp;eav=AfZFekSI4YDQuN5RSWFk09zfXYtN2mGYuu2oppnRqX8sTfs1DRN9WJYpG1ryN6G3pzo&amp;_rdr</a>
Peru	FAME Perú - Familias con Atrofia Muscular Espinal Perú (Families with SMA)	familiafameperu@gmail.com	Telephone: +51 934 105 732	<a href="https://www.facebook.com/FAMEPERU/">https://www.facebook.com/FAMEPERU/</a>
Peru	Esperantra-COPEPOFRE (Peruvian Coalition for Rare Diseases)	patients@esperantra.org	Telephone: +51 1 765 6325	<a href="http://www.esperantra.org/">http://www.esperantra.org/</a>

Peru	FEPER - Federación Peruana de Enfermedades Raras (Federation of Rare Diseases)	enfermedadesrarasperu@gmail.com	Telephone: +51 1 795 0304	<a href="https://feperperu.org/">https://feperperu.org/</a>
Philippines	Stand for SMA Philippines	smaphilippinesgroup@gmail.com		<a href="https://www.facebook.com/standforsma/">https://www.facebook.com/standforsma/</a>
Philippines	PSOD - Philippine Society for Orphan Disorders, Inc.	info@psod.org.ph	Telephone: (02) 661 8935	<a href="http://www.psod.org.ph/">http://www.psod.org.ph/</a>
Poland	Fundacja SMA Poland (SMA Foundation)	info@fsma.pl	Telephone: 22 350 02 02	<a href="https://www.fsma.pl/">https://www.fsma.pl/</a>
Poland	Fundacja Pomocy Chorym na Zaniak Mięśni in Szczecin (Foundation to Help Muscular Disease)	biuro@miesnie.szczecin.pl	Telephone: 695 745 441	<a href="https://miesnie.szczecin.pl/">https://miesnie.szczecin.pl/</a>
Portugal	ANAME - Associação Nacional da Atrofia Muscular Espinhal	anameportugal@gmail.com & anamepor@anameportugal.pt	Telephone: 912126161	<a href="https://www.facebook.com/anamept/">https://www.facebook.com/anamept/</a> & <a href="https://anameportugal.pt/">https://anameportugal.pt/</a>
Portugal	Associação Portuguesa de Doentes Neuromusculares (Portuguese Neuromuscular Association)	info@apn.pt		<a href="http://apn.pt/apn/">http://apn.pt/apn/</a>
Romania	Asociatia SMACARE Romania (SMA Care Association)	smacare.romania@gmail.com		<a href="https://www.facebook.com/profile.php?id=100064267466594&amp;paipv=0&amp;eav=AfYadNVF6fZAJomjbxDPNhoZOppGuGFxQfXlaNM6z-r2vkAuxyfh7PvKb1wX9-dleRg">https://www.facebook.com/profile.php?id=100064267466594&amp;paipv=0&amp;eav=AfYadNVF6fZAJomjbxDPNhoZOppGuGFxQfXlaNM6z-r2vkAuxyfh7PvKb1wX9-dleRg</a>
Romania	Asociatia Familia SMA (SMA Family Association)	contact@familiasma.com	Telephone: 0721 577 029	<a href="https://familiasma.ro/">https://familiasma.ro/</a> & <a href="https://www.facebook.com/as.familiaSMA">https://www.facebook.com/as.familiaSMA</a>
Romania	Raul-Sebastian Association	asociatiaraulsebastian@gmail.com	Telephone: 0746.288.807	<a href="https://asociatiaraulsebastian.wordpress.com/contact/">https://asociatiaraulsebastian.wordpress.com/contact/</a>
Romania	Romanian National Alliance for Rare Diseases	<a href="http://www.bolirareromania.ro/contact">http://www.bolirareromania.ro/contact</a>	Telephone: 40260 610033	<a href="http://www.bolirareromania.ro/">http://www.bolirareromania.ro/</a>
Russia	SMA Family Foundation Russia	info@f-sma.ru	Telephone: 7 (495) 544-49-89	<a href="http://www.f-sma.ru">www.f-sma.ru</a> & <a href="https://www.facebook.com/smafamilyrussia/">https://www.facebook.com/smafamilyrussia/</a>
Serbia	SMA Srbija (SMA Serbia)	smasrbija@sma.org.rs & office@sma.org.rs		<a href="https://smasrbija.rs/en/support/">https://smasrbija.rs/en/support/</a> & <a href="https://www.facebook.com/smasrbija/">https://www.facebook.com/smasrbija/</a>
Serbia	NORBS - National Organization for Rare Diseases Serbia	office@norbs.rs & linijapomoci@norbs.rs	Telephone: 0800 333 103	<a href="https://norbs.rs/">https://norbs.rs/</a>

Singapore	Muscular Dystrophy Association of Singapore	mdas@mdas.org.sg	Telephone: (65) 6259 6933	<a href="https://www.mdas.org.sg/">https://www.mdas.org.sg/</a>
Slovakia	SMA Slovakia	info@sma-slovakia.sk	Telephone: 421 908 304 163	<a href="https://www.sma-slovakia.sk/">https://www.sma-slovakia.sk/</a>
Slovakia	Slovak Alliance of Rare Diseases	office@sazch.sk		<a href="http://sazch.sk/">http://sazch.sk/</a> & <a href="https://www.facebook.com/SlovenskaAlianciaZriedkavychChorob">https://www.facebook.com/SlovenskaAlianciaZriedkavychChorob</a>
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	<a href="http://www.drustvo-distrofikov.si/">http://www.drustvo-distrofikov.si/</a>
South Africa	Cure SMA South Africa			<a href="https://www.facebook.com/sma.community.za">https://www.facebook.com/sma.community.za</a>
South Africa	Rare Diseases South Africa	hello@rarediseases.co.za & <a href="https://www.rarediseases.co.za/contact-us">https://www.rarediseases.co.za/contact-us</a>	Telephone: +27 10 594 3844	<a href="http://www.rarediseases.co.za/">http://www.rarediseases.co.za/</a>
South Africa	Muscular Dystrophy Foundation of South Africa	gmnational@mdsa.org.za	Telephone: 011 472-9703	<a href="https://www.mdsa.org.za/">https://www.mdsa.org.za/</a>
Spain	FundAME (Spinal Muscular Atrophy Association)	organizacion@fundame.net	Telephone: 34 634238004	<a href="http://www.fundame.net">www.fundame.net</a>
Spain	ASEM Catalunya - Associacio Catalana de Persones Amb Malalties Neuromusculars (Association of People with Neuromuscular Diseases)	info@asemcatalunya.com	Telephone: 932 74 49 83/619 39 47 42	<a href="http://asemcatalunya.com/">http://asemcatalunya.com/</a>
Spain	ASEM Federation (Spanish Federation of Neuromuscular Diseases)	info@asem-esp.org	Telephone: 606588291	<a href="http://www.asem-esp.org/">http://www.asem-esp.org/</a>
Spain	Association of Rare Diseases D'Genes	info@dgenes.es	Telephone: 34968420287	<a href="https://www.dgenes.es/">https://www.dgenes.es/</a>
Spain	FEDER - Federacion Espanola de Enfermedades Raras (Spanish Federation of Rare Diseases)	<a href="https://www.enfermedades-raras.org/contacto">https://www.enfermedades-raras.org/contacto</a>	Telephone: 91 533 40 08	<a href="http://www.enfermedades-raras.org/">http://www.enfermedades-raras.org/</a>

Sweden	NSMA - Nätverket för Spinal Muskelatrofi (Spinal Muscular Atrophy Network Sweden)	info@nsma.se		nsma.nu & <a href="https://www.facebook.com/nsma.sverige">https://www.facebook.com/nsma.sverige</a>
Sweden	Sällsynta Diagnoser (Rare Diseases Sweden)	info@sallsyntadiagnoser.se	Telephone: 072-722 18 34	<a href="https://www.sallsyntadiagnoser.se/">https://www.sallsyntadiagnoser.se/</a>
Sweden	CSD - Centrum för Sällsynta Diagnoser i Samverkan (Center for Rare Diagnoses)	<a href="https://csdsamverkan.se/csdisverige/sjukvardsregionalacentrumforsallsyntadiagnoser.4.5d8a5cd41793ff87c4e5835.html">https://csdsamverkan.se/csdisverige/sjukvardsregionalacentrumforsallsyntadiagnoser.4.5d8a5cd41793ff87c4e5835.html</a>	Telephone: 46709645902	<a href="https://csdsamverkan.se/">https://csdsamverkan.se/</a> & <a href="https://www.facebook.com/NFSD.se">https://www.facebook.com/NFSD.se</a>
Switzerland	SMA Schweiz (SMA Switzerland)	info@sma-schweiz.ch		<a href="http://www.sma-schweiz.ch">www.sma-schweiz.ch</a>
Switzerland	ASRIMM - Association Suisse Romande Intervenante contre les Maladies neuroMusculaires (Association Suisse Romande Intervening Against NeuroMuscular Diseases)	info@asrimm.ch	Telephone: 41 24 420 78 00	<a href="https://www.asrimm.ch/">https://www.asrimm.ch/</a>
Switzerland	ProRaris Alliance for Rare Diseases Switzerland	contact@proraris.ch	Telephone: 021 887 68 86	<a href="https://www.proraris.ch/">https://www.proraris.ch/</a>
Taiwan	Become the Miracle Association	info@smabma.org	Telephone: 0902-380-591	<a href="http://www.smabma.org">www.smabma.org</a>
Taiwan	Taiwan Association of Spinal Muscular Atrophy Families	taiwansma@gmail.com	Telephone: 07-201-0675	<a href="https://www.taiwansma.org.tw/?p=hjpl&amp;hl=zh-tw">https://www.taiwansma.org.tw/?p=hjpl&amp;hl=zh-tw</a> & <a href="http://www.facebook.com/taiwansma/">http://www.facebook.com/taiwansma/</a>
Taiwan	Taiwan Foundation for Rare Disorders	tfrd@tfrd.org.tw	Telephone: 886-2-2521-0717	<a href="https://www.tfrd2.org.tw/tfrd_eng/">https://www.tfrd2.org.tw/tfrd_eng/</a>
Tanzania	Support Bridge for Students with Disabilities (SBSD)	info@sbsd.or.tz	Telephone: +255 688 237 275	<a href="http://www.sbsd.or.tz">www.sbsd.or.tz</a>
Thailand	Thai Rare Disease Foundation	thairaredisease.f@gmail.com	Telephone: 098-247-2520	<a href="http://thairdf.org/">http://thairdf.org/</a>
Tunisia	Association Tunisienne d'Amyotrophie Spinale (SMA Association of Tunisia)	association.sma.tunisie@gmail.com	Telephone: 216 53 434 377	<a href="https://www.facebook.com/p/Association-Tunisienne-dAmyotrophie-Spinale-100082159113965/?paipv=0&amp;eav=AfYQrdLQXujzIBC-f267-uYy5AxYakRuPDV3Ct0KGtdhMHwaiNnJhPw5BHzsP8OI_bM&amp;_rdr">https://www.facebook.com/p/Association-Tunisienne-dAmyotrophie-Spinale-100082159113965/?paipv=0&amp;eav=AfYQrdLQXujzIBC-f267-uYy5AxYakRuPDV3Ct0KGtdhMHwaiNnJhPw5BHzsP8OI_bM&amp;_rdr</a>

Turkey	SMA Benimle Yürü Derneği (SMA Walk With Me Association)	info@sby.org.tr & bilgi@sby.org.tr	Telephone: +90 (212) 812 53 53	<a href="https://smabenimleyuru.org.tr/iletisim/">https://smabenimleyuru.org.tr/iletisim/</a>
Turkey	Türkiye SMA Vakfı (Turkey SMA Foundation)	info@sma.org.tr	Telephone: 0 507 206 74 24	<a href="http://www.sma.org.tr/">http://www.sma.org.tr/</a>
Turkey	KASDER - Türkiye Kas Hastalıkları Derneği (Neuromuscular Association of Turkey)	info@kasder.org.tr	Telephone: +90 212 663 86 86	<a href="https://www.kasder.org.tr/">https://www.kasder.org.tr/</a>
Ukraine	CSMA - Children with SMA Foundation Ukraine	info@csma.org.ua	Telephone: 380503640673	<a href="http://www.csma.org.ua">www.csma.org.ua</a>
United Arab Emirates	UAE Rare Disease Society	<a href="https://uaerds.ae/site/index.php/en/contact-us-page">https://uaerds.ae/site/index.php/en/contact-us-page</a>	Telephone: 0097143986777	<a href="https://uaerds.ae/site/index.php/en/">https://uaerds.ae/site/index.php/en/</a>
United Kingdom	Spinal Muscular Atrophy UK	office@smauk.org.uk	Telephone: 01789 267520	<a href="https://smauk.org.uk/">https://smauk.org.uk/</a>
United Kingdom	Treat SMA UK	treatsma@treatsma.uk	Telephone: 0300 800 0202	<a href="https://www.treatsma.uk/">https://www.treatsma.uk/</a> & <a href="https://www.facebook.com/groups/treatsma.uk">https://www.facebook.com/groups/treatsma.uk</a>
United Kingdom	Genetic Alliance UK	contactus@geneticalliance.org.uk	Telephone: +44 (0) 20 7831 0883	<a href="https://geneticalliance.org.uk/">https://geneticalliance.org.uk/</a>
United Kingdom	Rare Disease UK	info@raredisease.org.uk	Telephone: 0300 124 0441	<a href="https://www.raredisease.org.uk/">https://www.raredisease.org.uk/</a>
Uruguay	FAME Uruguay - Familias de Atrofia Muscular Espinal (Families of SMA)	fameuruguay@gmail.com	Telephone: +598 94 410 865	<a href="http://fameuruguay.blogspot.com/">http://fameuruguay.blogspot.com/</a> & <a href="https://www.facebook.com/fameuruguay/?ref=search">https://www.facebook.com/fameuruguay/?ref=search</a>
Uruguay	ATUERU - Asociacion Todos Unidos Enfermedades Raras Uruguay (United Association of Rare Diseases)	contacto@atueru.org.uy	Telephone: +598 22001444	<a href="https://www.facebook.com/ATUERU/">https://www.facebook.com/ATUERU/</a> & <a href="https://atueru.org.uy/">https://atueru.org.uy/</a>
Uruguay	FUDI - Uruguayan Federation of Disability Institutions	ditecuruguay2002@gmail.com	Telephone: +598 - 99 757 971	<a href="https://ditecuruguay.org/">https://ditecuruguay.org/</a>
Venezuela	FAME Venezuela - Familias y Amigos de la Atrofia Muscular Espinal (Families of SMA)	venezuela@fame-fsma.org	Telephone: +58 412-7342554	<a href="https://www.facebook.com/FAMECurAME/">https://www.facebook.com/FAMECurAME/</a>

Vietnam	VORD - Vietnamese Organization for Rare Diseases	info@rarediseases.vn	Telephone: +84 92 837 3532 / +84 94 293 05 10	rarediseases.vn
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