

Country	Site City	Site	Last name	First name	E-mail	Phone #
Austria	Krems an der Donau	Danube University Krems	Finsterer	Josef	fifigs1@yahoo.de	
Belgium	Ghent	University Hospitals	Deconinck	Nicolas		+32 2 477 3174
Belgium	Leuven	University Hospitals Leuven Children Hospital	Buyse	Gunnar	gunnar.buyse@uzleuven.be	+32 16 34 38 45
Belgium	Leuven	Universite Catholique de Louvain	Goemans	Nathalie	nathalie.goemans@uzleuven.be	+32 16 34 38 45/+32 16 34 06 43
Denmark	Copenhagen	University of Copenhagen	Vissing	John	vissing@rh.dk	+45 3545 2562
France	Bron	Hopital Femme-Mere-Enfant	Fontaine-Carbonnel	Stephanie		+33 4 72 12 94 50
France	Garches	Hopital Raymond Poincare	Estournet	Brigitte	brigitte.estournet@rpc.aphp.fr	
France	Grenoble	Chu De Grenoble	Lagrange	Emmeline	elagrange@chu-grenoble.fr	+33 4 76 76 66 61
France	Grenoble	Chu De Grenoble	Wuyam	Bernard	BWuyam@chu-grenoble.fr	+33 4 76 76 66 61
France	Lille	CHRU Hopital R. Salengro	Cuisset	Jean-Marie	jean-marie.cuisset@chru-lille.fr	+33 3 20 44 53 25
France	Lyon	Hospices Civils de Lyon	Vuillerot	Carole	carole.vuillerot@chu-lyon.fr	
France	Marseille	Hopital La Timone - Enfants	Chabrol	Brigitte	bchabrol@ap-hm.fr	+33 4 91 38 68 08
France	Montpellier	CHU de Montpellier, Hopital Gui de Chauliac	Rivier	Francois	f-rivier@chu-montpellier.fr	
France	Munich	Friedrich-Baur-Institute	Muller-Felber	Wolfgang	wolfgang.mueller-felber@med.uni-muenchen.de	+49 89 44005 7851
France	Paris	Hospital Armand Trousseau Pediatric Pulmonology Department And Ent Department	Fauroux	Brigitte	brigitte.fauroux@trs.aphp.fr	+33 1 44 73 66 68
France	Paris	Tenon Hospital Aphp	St Guily	Jean	jean.lacau@tnn.aphp.fr	
France	Paris	Croupe Hospital Pitie Slapetriere Institute De Myologie	Voit	Thomas	t.voit@institut-myologie.org	+33 1 421 657 35
France	Paris	Group hospitalier ArMand Trousseau	Mayer	Michele		+33 144 736 575
France	Paris	Institut de Myologie	Servais	Laurent	l.servais@institut-myologie.org	
France	Saint Etienne	Chu De Saint Etienne	Antoine	Jean-Christophe	j.christophe.antoine@chu-st-etienne.fr	+33 4 77 12 78 05
Germany	Berlin	Charite University Berlin	Grieben	Ulrike	ulrike.grieben@charite.de	+49 30 450 5405 27
Germany	Berlin	Charité Universitätsmedizin Berlin Department Neurology	Paul	Friedemann	friedemann.paul@charite.de	+49 30 450 539 705
Germany	Essen	Dept Neuropaediatrics University Essen University Clinical for Children	Schara	Ulrike	ulrike.schara@uk-essen.de	
Germany	Freiburg	Universitat Klinikum Freiburg	Kirschner	Janbernd		
Germany	Munchen	Friedrich-Baur-Institute	Walter	Maggie	maggie.walter@lrz.uni-muenchen.de	+49 89 5160 7400
Hungary	Budapest	Heim Pal Children's Hospital	Herczegfalvi	Agnes	aherczeg@t-online.hu	
Italy	Ferrara	University of Ferrara	Merlini	Luciano	luciano.merlini@unife.it	
Italy	Genova	Instituto Giannina Gaslini	Bruno	Claudio	claudiobruno@ospedale-gaslini.ge.it	
Italy	Messina	AOU Policlinico	Vita	Giuseppe	vitaq@unime.it	+39 090 221 2793
Italy	Messina	University of Messina, AOU Policlinico	Messina	Sonia		+39 090 221 2793
Italy	Milano	Centro Dino Ferrari	Comi	Giacomo Pietro	giacomo.comi@unimi.it	
Italy	Milano	NeuroMuscular Omnicenter (NEMO)	Corbo	Massimo		
Italy	Rome	Unione Italiana Lotta Distrofia Muscolare	Giglio	Vincenzo	giglio.echo@libero.it	
Italy	Rome	Unione Italiana Lotta Distrofia Muscolare	Mangiola	Fortunato	fortunato.mangiola@uildmlazio.org	
Italy	Rome	Policlinico Gemelli	Mercuri	Eugenio	mercuri@unicatt.rm.it	+39 06 3015 5340
Italy	Rome	Bambino Gesu Research Children's Hospital	Bertini	Enrico	enricosilvia.bertini@opbq.net	+39 06 6859 2104
Netherlands	Leiden	Leiden University Medical Center	Overweg-Plandsoen	Truus		
Netherlands	Leiden	Leiden University Medical Center	Straathof	Chiara		
Netherlands	Sneek	Timpaan Welzijn	Van Der Kooi	Anneke	a.vanderkooi@timpaanwelzijn.nl	+39 06 2500 0677
Netherlands	Utrecht	University Medical Center Utrecht	van den Berg	Leonard	lberg@umcutrecht.nl	+31 88 7557939
Russia	Moscow	Moscow Region Pediatric Psychoneurological	Artemieva	Svetlana	artemievasb@mail.ru	+7 499 905 9555
Switzerland	Lausanne	Dr Pierre Yves Jeannet Médecin Associé Mer	Jeannet	Pierre-Yves	pierre-yves.jeannet@chuv.ch	
UK	Birmingham	Heart of England NHS Foundation Trust - Heartlands Hospital	Ropper	Helen	helen.roper@heartofengland.nhs.uk	
UK	Birmingham	Birmingham Heartlands Hospital	Roper	Helen		+44 1 21 424 3687
UK	London	UCL Institute Child Health, Great Ormond St Hospital Child Gosh	Muntoni	Francesco	f.muntoni@ich.ucl.ac.uk	+44 20 7905 2111
UK	Newcastle Upon Tyne	NewCastle University, Royal Victoria Infirmary	Bushby	Kate	kate.bushby@ncl.ac.uk	+44 1 91 241 8757

UK	Newcastle Upon Tyne	Institute of Genetics	Lochmuller	Hanns		+44 1 91 241 8757
UK	Wales	Spire Cardiff Hospital	Hartley	Louise	m.helman@btinternet.com	+44 29 2073 6011