

**INTERNATIONAL ALLIANCE
OF
ALS/MND ASSOCIATIONS**



2010

DIRECTORY

**of Associations for People with
Amyotrophic Lateral Sclerosis / Motor Neurone Disease**

www.alsmndalliance.org

www.mndallianceresources.org

alliance@alsmndalliance.org

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Amyotrophic lateral sclerosis, or motor neurone disease, is a muscle wasting condition that affects individuals and those who care for them across the world. To help people with the disease, groups of people have joined to form associations that are listed in this directory.

The International Alliance of ALS/MND Associations was founded in November 1992 to provide a forum for support and the exchange of information between the worldwide associations. This directory has been produced by the International Alliance. Associations are listed with their current membership status, as indicated below:

Members

AUSTRALIA

Association: **Motor Neurone Disease Association of Australia Inc (MND Australia)**

Address: P.O. Box 785
Gladesville NSW 1675
Australia







Contact: Carol Birks, David Ali Alliance Representatives
Ralph Warren, Chairman/President

Tel: 61298165322
Fax: 61298162077

Email: carolb@mndaust.asn.au
David.Ali@dhs.vic.gov.au

Website: www.mndaust.asn.au

Region: Australia
Founded: 1991
Branches: 7 State and Territory Associations
2 Associate Member Organisations

- Activities:
-  Represents member organisation in national issues
 -  Represents Australia in global ALS/MND issues, through the International Alliance
 -  Undertakes development in national resources, particularly literature leaflets:
 - MND 'Some Facts' and 'More Facts'** (endorsed by the Australian Association for Neurologists)
 - Kennedy's Disease**
 - Guidelines for Predictive Testing for Familial MND**
 - MND – A Problem Solving Approach** (adapted with permission from an MND Association, UK and publication endorsed by the Royal Australian College of General Practitioners)
 -  Funds national research projects
 -  Acts as a clearing house for sharing State initiatives
 -  Promotes MND awareness, particularly to Federal Government, and via national media, especially during MND Week and ALS/MND Global Awareness Day (21 June)

Member Organisation services include:

- 🌐 Personal and telephone support
- 🌐 Information (printed, Internet and direct, newsletters)
- 🌐 Needs identification and co-ordination of service delivery to clients
- 🌐 Loan of disability aids and equipment
- 🌐 Education for health professionals and other service providers
- 🌐 Member meetings, via metropolitan and rural support group networks
- 🌐 Promoting MND awareness to State Governments and the general community

Status: **Full Member**

BELGIUM

Association: **ALS Liga België VZW (ALS Ligue Belgium)**

Address: Kapucijnenvoer 33 bus 1
B-3000 Leuven
Belgium

Contact: Evy Reviere, Director

Tel: +32 (0) 16 23 95 82

Fax: +32 (0) 16 29 98 65

Email: info@ALSLIGA.be or secretariaat@ALSLIGA.be

Website: www.ALSLIGA.be

Region: Belgium

In Belgium there lives 11 million people and those people speak 3 languages. Belgium is divided into three districts and all three districts have their own parliament.

So every district has their own laws. For us it isn't easy to give every patient information in their own language. It is also difficult for us to go to every district to advocate the rights of the patients.

But still we keep the fight for our 1,00 patients and we don't let us be discouraged by the complexity of our country!

Founded: May 1995

Branches: None

Activities: 🌐 To give information about ALS disease to patient, family members and other People

- 🌐 To provide psychosocial support to patients and family after diagnosis
- 🌐 Collect, translate, organize and distribute information
- 🌐 To provide equipment for free, like speech computers, wheelchairs, lifting-systems etc
- 🌐 To advocate the rights of ALS patients with various institutions and government
- 🌐 To aim for a customized reception and care by establishing a private care hotel
- 🌐 To organize contact days in order to promote the sense of community
- 🌐 Make the public aware of ALS
- 🌐 To establish contacts with foreign organizations in order to gather and exchange information
- 🌐 To operate our own secretariat
- 🌐 To publish our three monthly newsletter
- 🌐 To maintain the website www.alsliga.be

Status: **Full Member**

BRAZIL

Association: **Associação Brasileira de Esclerose Lateral Amiotrófica (Amyotrophic Lateral Sclerosis Brazilian Association) – ABrELA**

Address: Rua Estado de Israel,
899 - Vila Clementino
04022-002 São Paulo-SP
Brazil

Contacts: Acary Souza Bulle Oliveira – Founder President
Abrahão A.J. Quadros – President Director
Roberto Dias Bastista Pereira – Scientific Director
Elica Fernandes – Executive and Social Manager

Tel: 55 – 11 – 5579 4902
Fax: 55 – 11 – 5579 2668

Email: abrela@abrela.org.br
Website: www.abrela.com.br

www.tudosobreela.com.br

Region: Brazil
Founded: 13 March 1998
Branches: 2 Regional ALS Regional Association (ARELA)
1- ARELA/RS and 2-ARELA/MG

- Activities:
- 🌐 Personal and telephone support
 - 🌐 Social service attendance
 - 🌐 Registration of ALS patients
 - 🌐 Performing social and humanitarian activities
 - 🌐 Bimonthly meeting support – information about the disease and treatment for patients, caregiver, familial and health professional
 - 🌐 Co-ordinate volunteers to provide support and raise funds
 - 🌐 Loan of disability aids and equipment
 - 🌐 Promoting annual national symposium on MND/ALS
 - 🌐 Information (booklets, publication, internet)

Status: **Full Member**

CANADA

Association: **ALS Society of Canada**

Address: 3000 Steeles Avenue East
Suite 200
Markham
Ontario
L3R 4T9
Canada

Contact: David Cameron, President and CEO Alliance Representative







Tel: +1 905 248 2052
Fax: +1 905 248 2019
Toll Free: 1 800 267 4257

Email: alscanada@als.ca

Email: dc@als.ca (David Cameron)
Website: www.als.ca

Region: Canada
Founded: 1977
Branches: 10 Regional/Provincial Units; 30 Chapters

Activities:

-  Fund Research
-  Provide support to Units
-  Provide patient/client information
-  Advocacy
-  Government relations
-  Build awareness of ALS

Status: **Full Member**

CROATIA

Association: **Union of Muscular Dystrophy Societies of Croatia**

Address: Nova Ves 44
10000 Zagreb
Croatia

Contact: Marica Miric, President
Marija Sostarko, Medical Advisor



Tel/Fax: +385 98 218 644
Tel: +385 1 461 6046 (Marija Sostarko)
Fax: +385 1 461 6045 (Marija Sostarko)

Email: sddh@zg.t-com.hr

Website: www.sddh.hr

Region: Croatia
Founded: 1970
Branches: 17

Activities:

-  Gathering together patients and family members with doctors to talk more about neuromuscular disease and its problems for members
-  Information on neuromuscular diseases

- 🌐 Performing social and humanitarian activities
- 🌐 Supporting the permanent aid to neuromuscular patients
- 🌐 Quarterly newsletter
- 🌐 Organisation of summer holidays, concerts, picnics and other celebrations

Status: **Full Member**

DENMARK

Association: **Muskelsvindfonden**

Address: Kongsvang Alle 23
DK-8000
Aarhus C
Denmark

Contact: Jette Møller, Alliance Representative

Tel: +45 89 48 22 22
Fax: +45 89 48 22 12

Email: reception@muskelsvindfonden.dk
Email: jemo@rcfm.dk
Website: www.muskelsvindfonden.dk

Region: Denmark
Founded: 1971
Branches: 2

Activities:

- 🌐 Arranging and supporting national and international meetings for people with ALS and their spouses
- 🌐 Arranging courses for people with ALS, their families and helpers
- 🌐 Devising and promoting standards of respiratory and practical care
- 🌐 Setting up support groups
- 🌐 Founded Rehabilitation Centre for Neuromuscular Diseases which offers the following activities for the Danish population with ALS:

🌐 ALS-consultants providing following tasks:

- Ensure that families with ALS receive the best possible care
- Offer advice and information for health and social care professionals and people affected by ALS/MND
- Produce leaflets and publications about the disease and good practice in relation to ALS
- Arrange home visits and information meetings with local authorities
- Arrange courses and theme meetings for persons with ALS and their families
- Coordinate support and treatment of ALS patients with the ALS team in hospitals
- Carry out research and developmental work in relation to rehabilitation of ALS/MND patients

Status: **Full Member**

ENGLAND, WALES & NORTHERN IRELAND

Association: **Motor Neurone Disease Association (MND Association)**

Address: PO Box 246
Northampton
NN1 2PR
United Kingdom

Contact: Kirstine Knox, Chief Executive
Alan Graham, Alliance Board Member

Tel: +44 1604 250505
Fax: +44 1604 611852

Email: enquiries@mndassociation.org

Website: www.mndassociation.org

Region: England, Wales, Northern Ireland (the Isle of Man and Channel Islands – affiliated Branches)

Founded: 1979

Branches: 80

- Activities:
- 🌐 In contact with approx 2,600 people with ALS/MND at any one time
 - 🌐 Helpline for people with ALS/MND and their carers
 - 🌐 Advice and information for health & social care professionals and people affected by ALS/MND
 - 🌐 Leaflets and publications on ALS/MND

- 🌐 Network of Regional Care Advisers supporting families with ALS/MND to ensure they receive the best possible care
- 🌐 Equipment Loan
- 🌐 Financial Support
- 🌐 Established a national network of 14 MND Care Centres. These:
 - provide coordinated integrated care
 - act as a tertiary Centre
 - provide educational opportunities and disseminate good practice
 - may run clinical drug trials, and/or carry out research
- 🌐 Branches providing support and raising funds
- 🌐 Network of Association Visitors offering understanding & befriending support to families affected by the disease
- 🌐 Developed award winning training programme for Association Visitors
- 🌐 Educational programme for health and social care professionals, people living with ALS/MND, carers and members of the Association
- 🌐 Developing guidelines on the clinical management of ALS/MND. Current modules are
 - Time to, and telling the diagnosis
 - Nutritional management
 - Respiratory management
- 🌐 Devised and promoting implementation of Standards of Care
- 🌐 Standards of Care audit tool developed for health and social care professionals
- 🌐 Collate data on experiences of people living with ALS/MND and carers (alternate years to ascertain their ability to access the recommended standards of care and quality of support via the Association)
- 🌐 Fund research into all aspects of pure and applied research; approximately 20 research grants at any one time
- 🌐 Devised and currently implementing Care and Influencing strategy
- 🌐 Annual ALS/MND week, to raise awareness of the disease and raise the profile of Branches by hosting co-ordinated local events

Status: **Full Member**

FINLAND

Association: **The Finnish Neuromuscular Disorders Association (Lihastautiliitto ry)**

Address: Läntinen Pitkäkatu 35
20100 Turku
Finland

Contact: Sinikka Loukamaa

Tel: +358 2 2739700

Fax: +358 2 2739701









Email: sinikka.loukamaa@lihastautiliitto.fi

Website: www.lihastautiliitto.fi

Region: Finland

Founded: 1972

Branches: 12

- Activities:
-  Information booklets and publications on ALS
 -  Support groups
 -  Information services for patients and professionals
 -  Advice to people with ALS, their families and professionals
 -  Courses for people with ALS and their families
 -  Clinic for neuromuscular patients
 -  Physiotherapy institute
 -  National ALS-day once a year for patients and their families

Status: **Full Member**

FRANCE

Association: **Association pour la Recherche sur la Sclérose Latérale Amyotrophique (ARS)**









Address: 75 avenue de la République
75011
Paris
France

Contact: Emmanuel Hirsch, Présidente
Prof. Vincent Meininger, Alliance Representative

Tel: +33 1 43 38 99 11
Fax: +33 1 43 38 31 59

Email: ars@wanadoo.fr
Website: www.ars-asso.fr

Region: France
Founded: 1985
Branches: 16

Activities:  Supporting Group
 Information on MND/ALS to the public, families and patients
 Telephone helpline
 Welfare assistance
 Training of carers
 Production of technical leaflets
 Research funding
 Quarterly and annual publications

Status: Full Member

GERMANY

Association: **Deutsche Gesellschaft für Muskelkranke e.V.DGM**









Address: Im Moos 4
79112 Freiburg
Germany

Contact: Horst Ganter, Managing Director

Tel: +49 76 65 94 470
Fax: +49 76 65 94 4720

Email: info@dgm.org
Website: www.dgm.org

Region: Germany
Founded: 1965
Branches: 18

- Activities:
-  Information on neuromuscular disorders to the public, families and patients
 -  Welfare assistance
 -  Training of carers
 -  Research funding
 -  Quarterly publications
 -  Neuromuscular centres all over Germany
 -  Scientific committee with about 200 specialists
 -  Special information services for MND/ALS patients and families concerning medical treatment, rehabilitation and all forms of help in daily life

Status: **Full Member**

HONG KONG

Association: **Hong Kong Neuro-Muscular Disease Association**



Address: G/F, Wang Tau Hom Estate
Kowloon
Hong Kong SAR
PRC China

Contact: Peter Poon Ka Wing (Vice-Chairman)
Gigi Yueng, Project Officer (Social Worker)

Tel: +852 2338 4123
Fax: +852 2338 2410

Email: hknmda@netvigator.com

Region: Hong Kong Special Administration Region of People's Republic of China
Founded: November 1998

- Activities:
-  To establish and enhance the networks with related institutes and professionals for case referral, information sharing and joint venture
 -  To liaise with funding bodies for stable donation and sponsorship

- 🌐 To communicate with other patient self-help organizations on medical, health and social welfare policies and services
- 🌐 To publish member newsletters regularly for enhancing the connection with members and providing updated information
- 🌐 To provide local and overseas information about the disease, treatments and social resources
- 🌐 To invite medical, health and social professionals as the professional advisors of the Association
- 🌐 To provide service in different regions – Hong Kong Island, Kowloon East, Kowloon Central, New Territories East and New Territories West regions
- 🌐 To organise community educational programmes or seminars
- 🌐 To make use of mass media to arouse public concern on the needs of patients and carers
- 🌐 To arrange friendly visits to hospital, speciality out-patient clinics, allied health departments and special schools
- 🌐 Medication and medical treatment
- 🌐 Integrated social rehabilitation programme, day care centre and residential care, especially for adult patients
- 🌐 Accessibility and public transportation
- 🌐 Rehabilitation and psycho-social programme
- 🌐 Talks, workshops and seminars
- 🌐 Regular gatherings
- 🌐 Social and recreational activities
- 🌐 Educational package and materials
- 🌐 Social concern group on related policy and service
- 🌐 Volunteer service and concern visit
- 🌐 District-based small mutual support group

Status: **Associate Member**

ICELAND

Association: **MND Association of Iceland**

Address: P.O. Box 94
222 Hafnarfjörður
Iceland

Contact: Gudjon Sigurdsson

Tel: +354 565 5727







Email: mnd@mnd.is

Website: www.mnd.is

Region: Iceland

Founded: February 1993

Branches: 1

- Activities:
-  We have an office open twice a week
 -  Helpline support to patients and carers and families
 -  Information about the disease and information update
 -  Newsletter twice a year
 -  In 1998, produced a documentary film for Icelandic TV about the disease featuring people with MND
 -  Meetings Support Groups

Status: **Full Member**

INDIA

Association: **Motor Neurone Disease Association of India**

Address: 40 Kolagarh Road
Street No 5
Dehradun
UN 248001
India

Contact: Nicky Bhagat

Tel: +91 (135) 2754487

Email: nikinam@gmail.com

- Activities:
- 🌐 To promote the welfare of people with ALS/MND.
 - 🌐 To encourage rehabilitation of people with ALS/MND on self basis by bringing together people with ALS/MND and their families and medical professionals, physiotherapists, etc through referrals for counselling, training and support on how to cope with ALS/MND. Providing care through ALS/MND centres.
 - 🌐 To help people with ALSMND understand and accept the realities of ALS/MND and foster a determination in them to lead the most optimum life consistent with their self respect and happiness.
 - 🌐 To propagate and enlighten the public about the existence and gravity of ALS/MND so that society accepts and integrates people with ALS/MND as valuable citizen capable of growth to their fullest potential
 - 🌐 To serve as a National Information Bank on ALS/MND for the medical profession, patients and family members and research organisations worldwide.
 - 🌐 To promote activities intended to assist people with ALS/MND through treatment and medication and to make available aids and printed recourses for the management keeping in mind factors of economy and appropriate indigenous technology. To translate the manual on disease management of ALS/MND into the vernacular and made them available where needed.

Status: **Full Member**

IRELAND

Association: **Irish Motor Neurone Disease Association**

Address: Coleraine House
Coleraine Street
Dublin 7
Ireland

Contact: Ciara Hudson, Manager


Tel: +353 1 873 0422

Fax: +353 1 873 1409

Email: info@imnda.ie
Website: www.imnda.ie

Region: Republic of Ireland
N.B. Northern Ireland is covered by the MND Association, England, Wales and Northern Ireland

Founded: May 1985

Activities:  The Association functions as a support organisation for people with MND, their carers and families. Our work entails the co-ordination of home-care services and facilities, information service, financial assistance for home nursing or care and the supply of specialised equipment and aids on loan to patients. We also support research into the causes and treatment of MND and fund a liaison nurse who helps to co-ordinate patient services. Our aims and objectives are to endeavour to support all those people directly or indirectly affected by MND. We not only offer financial assistance for care but also provide essential information and communication services of help and advice for people with MND and their carers.

Status: **Full Member**

Association: **The Irish Motor Neurone Disease Research Foundation**

Address: Clinical Research and Education Centre
Smurfit Building
Beaumont Hospital
Beaumont
Dublin 9
Ireland

Contact: Catherine Lynch, CEO

Tel: +353 1809 3874

Fax: +353 1809 3809


Email: mndregister@gmail.com

Website: www.mnd.ie

Region: South of Ireland

Founded: 2007

Branches: 1

Activities:  **Services Provided**
The Irish MND Research Group provides multidisciplinary service to the population of patients with ALS (circa 4 million). Approximately 80% of all ALS patients in Ireland are in contact with the service, which is the only dedicated ALS facility in the country. The services has an immediate access policy to our weekly ALS clinic – thus providing services to new patients within 2-4 weeks of initial referral

(compared to 12 months for an average patient requiring neurological assessment in Ireland). Return patients are seen at regular intervals of between 6 weeks and 3 months. The multidisciplinary support includes same day review by specialist physiotherapy, occupational therapy, speech & language therapy, dietetics and specialist nursing.

The clinic has access to a wide range of in-patient and out-patient facilities for diagnostic and management purposes.

In-patient facilities are provided in a dedicated neuroscience unit with specialist nurses with on-site access to a full range of palliative care services, specialist interventional radiology (for radiologic inserted gastrostomy) access to a specialist respiratory physician with a specific interest in ventilatory failure). A full service in neuropsychology and neuropsychiatry is also available.

Home visits are provided by specialist nurses and clinical Fellows, and the services work closely with outreach teams provided by Palliative care.

24 hour advice is available by phone through a mobile phone helpline (provided during working hours by specialist nurses) and an out-of-hours service provided the neurology service within the Hospital

The service also provides online support and advice through its website (www.mnd.ie) and works closely with the voluntary organization, the Irish Motor Neurone Disease Association.



Research

The Irish Motor Neurone Disease Research Group has a strong track record in research.



Clinical Research

The Irish MND Research Group has set up and maintained for 15 years the longest running population-based Register of ALS in the world.

The Register is now part of the European ALS (EURALS) group, of which we are a founder member.

Our group undertook the first analysis of the El Escorial criteria, demonstrating that the criteria are not predictive of survival, and that up to 25% of patients with ALS remain ineligible for inclusion in clinical trials at time of death.

We were the first to demonstrate that attendance at a multidisciplinary clinic is an independent determinant of outcome, and we later demonstrated a significant difference in outcome between incident and prevalent populations. We have demonstrated superiority of RIG over PEG, the benefits of individualised quality of life measures, and the superiority of SNIP over Vital Capacity as a predictor of survival.

Significance: Our clinical research has changed practice.



Genetics Research

We have capitalized on the relative homogeneity of the Irish population. We identified a series of novel mutations in ANG. Replication has been achieved in at least 4 other populations, where ANG mutations account for approximately 1% of all sporadic ALS. Subsequent work has shown that angiogenin promotes neurite outgrowth and has neuroprotective properties that can be exploited to therapeutic effect.

We have identified and tested for replication a number of susceptibility genes in sporadic ALS in Irish, English, Scottish, US and Polish patients, including APEX, angiogenin, HFE, PON, DPP6, and a variety of hypoxia responsive genes.



Significance

Our work has demonstrated that small well-characterized homogeneous populations can successfully identify important new loci. We have demonstrated that population differences may confound successful replication of novel candidate genes that alter disease susceptibility in individual ancestral populations.



ALS And Cognitive Impairment

We have undertaken the first detailed population-based longitudinal survey of cognition in ALS. Our preliminary data suggest that cognitive impairment in ALS occurs in approximately 40% of those with ALS, and that it occurs early in the illness.



We have demonstrated that those with normal cognition at diagnosis are unlikely to progress to develop cognitive impairment.

Significance: Our evidence suggests that ALS and ALS/FTD do not form a continuum, and may have different genetic substrates.

Our work has generated an important resource of DNA from patients followed longitudinally with detailed neuropsychological profiling.



World ALS

We were the first group to undertake a systematic review of the impact of ethnicity on ALS epidemiology.

We are working closely with collaborators in "New Europe" and developing countries to develop help advance research in clinical management, epidemiology and genetics.

With collaborators in Cuba, we have shown that corrected mortality rates for ALS in admixed populations are approximately 3 times lower than in ancestral Europeans, and lowest in the "mixed" population.

This is the first robust evidence that the incidence of ALS differs among ancestral populations.

Our group has also helped to design and fund a prospective population-based incidence study of ALS in Cuba, including DNA collection. The aim is twofold:

1. To develop services for ALS and other neurodegenerative diseases in Cuba
2. To determine the incidence, prevalence, clinical features and outcome of this admixed population.

Significance: Our objective is to establish a multi-national clinical and genetic dataset that will determine the effects of ancestral origin on clinical phenotype and genetic susceptibility, and that will allow identification of possible novel susceptibility and protective genes.







Status:

Full Member

ISRAEL

Association:	IsrA.L.S
Address:	22 Shvedia Street Haifa 34980 Israel
Contact:	Efrat Carmi, CEO
Tel:	+972 4 8252233
Email:	efrat@israls.org.il (Efrat Carmi)
Website:	www.israls.org
Region:	Israel
Founded:	March 2004
Branches	2
Activities:	<ul style="list-style-type: none"> Funding research for companies and bodies who are interested in Conducting research into ALS/MND Approaching researchers and pharmaceuticals to encourage research into ALS/MND Increasing awareness of ALS/MND among the public, researchers and donors Publishing via our website information on basic and clinical research that is conducted in Israel Publishing information on ALS/MND, the activities of the organisation and its achievements Forum of Professionals who respond to questions and queries via our website
Status:	Associate Member

ITALY

Association:	Associazione Italiana Sclerosi Laterale Amiotrofica (AISLA)
Address:	Viale Roma 32 28100 Novara Italy
Contact:	Dr. Mario Giovanni Melazzini, President Lea Gavin, Secretary Monica Cattani, Alliance Representative
Tel:	+39 0321 499727
Fax:	+39 0321 499719
Email:	segreteria@aisla.it
Website:	www.aisla.it
Region:	Italy
Founded:	April 1983
Branches:	15
Activities:	<ul style="list-style-type: none"> Raise awareness of the disease Inform and support patients and their families (bulletins, meetings) Refer patients to centers and local support groups Fund research Promote contact and cooperation with sister organisations in other countries <i>Notiziario AISLA</i> bulletin with six issues a year, meetings
Status:	Full Member

JAPAN

Association: **Japan ALS Association**

Address: Zuicho Building 101
1-15-15 Kudankita
Chiyoda-ku Tokyo
102-0073 Japan

Contact: Mr Kimiaki Kanazawa, Secretary General

Tel: +81 3 3234 9155

Fax: +81 3 3234 9156

Email: jalsa@jade.dti.ne.jp

Website: www.alsjapan.org

Region: Japan

Founded: April 1986

Branches: 32

- Activities:
-  Educating the public about ALS/MND
 -  Collecting and disseminating information about ALS/MND
 -  Lobbying for Government action to improve medical and welfare systems and to accord full political participation to PALS
 -  Managing research scholarship (JALSA Fund established 1994) to promote scientific research and care skills
 -  Providing consultations to PALS and their families and helping them gain better communication equipment
 -  Publishing care manuals and organizing training seminars
 -  Publishing a quarterly bulletin 'JALSA'
 -  Participating in international activities to exchange information and to work together to conquer ALS
 -  Working towards the goal of establishing a society where PALS can live with dignity

Status: **Full Member**

KOREA

Association: **Korean ALS Association**













Address: Korea ALS Association Building

Seocho-Ku Bangbae-Dong
906-5
Seoul, 137-842
South Korea

Contact: Kwang-Woo Lee
Professor of Seoul National University College of Medicine
Chairman of Seoul National Hospital Department of Neurology

Tel: + 82 2 760 3880
Fax: +82 2 744 1785
Email: kwoo@plaza.snu.ac.kr

Region: South Korea
Founded: May 2001
Branches: 14
Activities:

-  Education of families, caregivers, hospitals and organizations which serve ALS patients
-  Education and support of the patients with ALS and families
-  Development of medical system to diagnose early ALS patients
-  Registration of ALS patients
-  Develop equipment and facilities for management
-  Establishment of a system of diagnosis and treatment
-  Support of basic and clinical researchers of ALS
-  Communication with ALS related organizations from other countries
-  Education of general public for settling the issues associated ALS patients and families
-  Support of the development of governmental policies for ALS
-  Publication of a Bulletin
-  Support of caregivers for poor families
-  Education of and communication with patients, families and the general public by website

Status: **Full Member**

MEXICO

Association: **Familiares y Amigos de Enfermos de la Neurona Motora AC (Fyadenmac)**

Address: Enrique Faman No 164-B
Col Aviación Civil
Mexico 15740 DF

Contact: Mr Armando Nava Escobedo, President

Tel: +52 5 115 12 85







Fax: +52 5 115 12 86

Email: administracion@fyadenmac.com, pacientes@fyadenmac.org

Website: www.fyadenmac.org

Region: México (Estados Unidos Mexicanos)

Founded: June 1982

- Activities:
-  Publishing of information about ALS
 -  Finance research in co-operation with neurosurgery hospital
 -  Finance scholarships to students of neurology
 -  Voluntary visits to patients; psychological help (patients and carers)
 -  Provide equipment for a better care at home of the patient (chairs, respirators, aspirators, beds, etc)
 -  Twice a year meetings with patients, relatives and the voluntary group

All these services are free for patients and relatives; the Association collects funds by auction sales and donations

Status: **Full Member**

REPUBLIC OF MOLDOVA






Association: Moldavian Myopathy Association

Address: 24 A1 Bulgara str.
Chishinau
MD-2001
Republic of Moldova

Contact: Maria Tonu

Tel: +373 2 27 26 87

Email: mtonu@mail.md

- Activities:
-  The scientific study of cases of neuromuscular disorders on the whole territory of Moldavia
 -  The specialised medico-social system for persons with neuro-muscular disorders
 -  The National Program for fighting against neuro-muscular disorders
 -  National scientifico-practical conferences
 -  Founded Center of Information and Communication through computers

Status: **Full Member**

MONGOLIA





Association: **Mongolian ALS Association**

Address: PO Box 22
Chinggis Avenue
Khan-Uul District
Ulaanbaatar 210644
Mongolia

Tel: 00976-11362757

Email: alsmongolia@yahoo.com

Region: Mongolia
Founded: April 2004

- Activities:
-  Improving awareness of ALS in Mongolia
 -  Caring for people affected by ALS by providing support and service to them
 -  Educating health and social professionals about ALS
 -  Raising fund for these activities

Status: **Associate Member**

NETHERLANDS

Association: **Vereniging Spierziekten Nederland - VSN (ALS Diagnostic Support Group)**

Address: van Heutszlaan 6
3743 JN Baarn
The Netherlands

Contact: Ria Broekgaarden

Tel/Fax: +31 33 480 2016






Email: ria.broekgaarden@vsn.nl

Website: www.vsn.nl

Region: The Netherlands

Founded: September 1967

Branches: 10 regions, 13 diagnostic support groups

- Activities:
-  Stimulating research
 -  Publishing of information about the disease MND/ALS and medical developments
 -  Organising information meetings
 -  Publishing of a quarterly newsletter
 -  Promoting contact and co-operation with sister organisations in other countries

Status: **Full Member**

Association: **Stichting ALS Nederland**

Address: Loolaan 31 A
7314 AB APELDOORN
The Netherlands

Contact: Madelon Swenker
Monique van Bijsterveld

Tel: +31 55 5266 500

Fax: +31 55 5266 501

Email: info@stichting-als.nl

Madelon@m-v-b.nl

Website: www.stichting-als.nl

Region: The Netherlands
Founded: January 2005
Branches: 4

- Activities:
- 🌐 Granting (financial) support to and promotion of research to causes of ALS and research to cure or prevent the disease
 - 🌐 Increase of available knowledge in this area by stimulating scientific research in a broad sense, particularly aimed at the cause and the prevention of ALS, but also on treatment and rehabilitation of patients.
 - 🌐 Making available information on the causes and treatment of ALS.
 - 🌐 Promotion training of experts both in the medical and non-medical disciplines and promotion of additional studying to doctors and others involved in care of patients
 - 🌐 Initiate and maintain contacts with institutions, organisations and agencies which can contribute to the fight of ALS/MND.
 - 🌐 Initiate and maintain contacts, and cooperate with pharmaceutical companies in areas where they contribute to the fight of ALSMND
 - 🌐 Doing advocacy for people with ALS in the broadest sense of the word.
 - 🌐 Maintain a knowledge centre on ALS.
 - 🌐 Stimulate awareness of ALS.
 - 🌐 Initiate, manage, develop funds to support all aforesaid objectives
 - 🌐 All other activities that contribute to the goals and objectives goals and objectives.

The foundation tries to reach these goals and objectives by all legitimate resources, such as,

- 🌐 Acquiring and invest reinvesting resources, and securities and its revenues.
- 🌐 Acquiring donations, legacy and heritages.
- 🌐 Fund raising in a broad sense of the word.
- 🌐 Granting benefits or supply loans to persons or institutions operative or doing research in the field of ALS/MND.

Status: **Associate Member**

NEW ZEALAND

Association: **Motor Neurone Disease Association of NZ**

Address: PO Box 24036, Royal Oak, Auckland 1453
14 Erson Avenue, Royal Oak, Auckland
New Zealand

Contact: Diane Robinson – National Manager

Tel: +64 9 624 2148

Fax: +64 9 624 2149


Email: mgr@mnda.org.nz


Website: www.mndanz.org.nz

Region: New Zealand


Founded: March 1985

Branches: 6

Activities:  Social, emotional and practical support

 Advocacy

 Awareness

 Provision of information

 Encouragement of research

Status: **Full Member**

SCOTLAND

Association: **MND Scotland**

Address: 76 Firhill Road
Glasgow
Scotland
G20 7BA

Contact: Craig Stockton, Chief Executive

Tel: +44 141 945 1077

Fax: +44 141 945 2578

Email: info@scotmnd.co.uk (General Correspondence)









Email: Craig.Stockton@scotmnd.co.uk(Craig Stockton)

Website: www.mndscotland.org.uk

Region: Scotland

Founded: 1981

Branches: 7

- Activities:
-  A network of MND clinical specialists throughout Scotland
 -  Specialist equipment loan service
 -  Study days for health and social care professionals
 -  Grants to individuals in need
 -  Raising awareness
 -  Co-ordinate volunteers to provide support and raise funds
 -  Library and information service, including quarterly newsletter, in-house publications and leaflets on MND/ALS
 -  Research promotion and funding, particularly research that will lead improved care and quality of life to those affected by MND/ALS

Status: **Full Member**

SLOVENIA

Association: **Drustvo Distrofikov Slovenije (Muscular Dystrophy Association of Slovenia)**

Address: Linhartova 1
1000 Ljubljana
Slovenia

Contact: Boris Sustarsic, President
Ivo Jakovljevic, Secretary
Andreja Sustar, Social Activities Organiser

Tel: +386 1 47 20 500

Tel: +386 1 47 20 552 (Andreja Sustar)

Fax: +386 1 43 28 142

Email: info@drustvo-distrofikov.si

Email: andreja.sustar@drustvo-distrofikov.si (Andreja Sustar)

Region: Slovenia

Founded: 1969
Branches: 2

Activities: We are fulfilling many things, not just in the health area but also areas such as economic relief, rehabilitation, education, living and social life. The association is independently carrying out some special social programs, such as our mobile service and health care service, which assures people with muscular dystrophy proper mobility and care. Enterprise for employing disabled people, Birografika Bori is realising its goals through successful marketing. The association is also performing maritime medical rehabilitation in Dom dva topola in Izola. We offer additional education, employment opportunities, informative magazines, technical facilities, sport, recreation and some free time activities.

Status: **Full Member**

SOUTH AFRICA

Association: Motor Neurone Disease Association of South Africa

Address: P.O. Box 789
Howard Place 7450
Western Cape
South Africa

Contact: Dr Franco Henning, Chairman
Rina Myburgh, Secretary

Tel: +021 531 6130
Fax: +021 531 6131

Email: mndaofsa@global.co.za
Website: www.mnda.org.za

Region: Republic of South Africa
Founded: February 1991
Branches: 2

Activities: We provide two sets of leaflets - one for patients and families and one for professionals. We publish a quarterly newsletter available to patients, families, professionals and all interested parties. We run an equipment loan scheme and advise on equipment needed. We counsel the patient and family and help create a team of supporters to surround the patient and family. We address institutions, Hospices, Rotary Clubs, Social Workers etc on MND - what it is, who it affects etc. We try to promote public awareness, although our day-to-day task is to try to keep abreast of the problems our patients have, as we are as yet a small group of people in a vast country.

Status: **Full Member**

SPAIN

Association: **Asociación Española de Esclerosis Lateral Amiotrófica (ADELA)**

Address: C/Hierbabuena
No 12 Local bajo Dcha
28039 Madrid

Contact: Adriana Guevara de Bonis, President

Tel: +34 91 311 3530











Fax: +34 91 459 3926

Email: adela@adelaweb.com

Website: www.adelaweb.com

Region: Spain

Founded: May 1990

- Activities:
-  Provides information and advice to people with ALS/MND and their families
 -  Coordinates activities of volunteers providing support and raising funds
 -  Supports network of regional care advisors in advising families and professionals
 -  Serves as a link for nationwide equipment loan scheme providing communication aids, chairs, bed elevators, etc
 -  Provides home care support
 -  Forms public opinion (newspapers, TV, Internet)
 -  Raises awareness of the disease
 -  Conducts conferences and courses (people with ALS/MND and their families, and health and social professionals)
 -  Provide support to specialists (occupational therapists, social workers, psychologists, language therapists, physiotherapists etc)
 -  Maintains contact with all Spanish people with ALS/MND and their families
Support to Spanish speaker associations

Status: **Full Member**

Association: **Fundacion Espanola para el Fomento de la Investigacion de la Esclerosis Lateral Amiotrofica (FUNDELA)**

Address: Calle Sinesio Delgado
10-28029 Madrid

Contact: Teresa Salas Campos, Co-ordinator

Tel: +34 91 453 2595





Fax: +34 91 733 6614

Email: fundela@fundela.info

Website: www.fundela.info

Region: Spain

Founded: September 2002

- Activities:
-  Total or partial projects and investigation financing
 -  To propagate updated scientific and clinical knowledge of the illness by way of realisation and/or sponsorship of conferences, trainings, editing books and magazines and scholarships for investigation or study
 -  Actions to make society aware and conscientious of the social-sanitary problems caused by this illness in order to procure donations from public and private institutions for investigation and for improving the quality of life of patients
 -  Proactive and mutual collaboration with associates or other organizations with the same objectives as the Foundation in order to achieve them sooner

Status: **Full Member**

SWEDEN

Association: **Neurologiskt Handikappades Riksforbund (NHR) Reference Group ALS**

Address: PO Box 49084
SE-100 28 Stockholm
Sweden

Contact: Mia Lundström

Tel: +46 8 677 70 10











Fax: +46 8 24 13 15

Email: nhr@nhr.se

Website: www.nhr.se

Region: Sweden

Branches: 100/21 Chapters
Founded: 1957

- Activities:
-  Information
 -  Legal help
 -  Theme meetings
 -  Symposiums
 -  Diagnosis courses
 -  Lobbying
 -  Recreation and outings
 -  Opinion work concerning research and rehabilitation
 -  Support for families
 -  Embodied in the NHR with its 100 branches and their members

Status: **Associate Member**

SWITZERLAND

Association: **Association de la Suisse Romande et Italienne contre les Myopathies (ASRIM)**

Address: 18 Route du Vignoble – 1175 Lavigny
Switzerland

Contact: Anne Humberst

Tel: +21 808 74 11

Fax: +21 808 81 11


Email: info@asrim.ch

Website: www.asrim.com

Region: French and Italian speaking parts of Switzerland

Founded: 1977

Branches: 1

Activities:  Patient information (literature, meetings, talks, conferences, bulletin medical revues, newsletters, holiday camps.)

- 🌐 Research support through grants, equipment, by our foundation of neuromuscular diseases
- 🌐 Financial help; neuromuscular consultation in university hospitals in Lausanne, Geneva, Lugano
- 🌐 Research fundings by Telethon
- 🌐 Financial support for following-up children with neuromuscular diseases to the university orthopedical hospital
- 🌐 Financial support for developing auxiliary equipment
- 🌐 Information on neuromuscular diseases to the public, medical and paramedical personal
- 🌐 Activities with umbrella associations on national level to eliminate discrimination for handicapped people

Status: **Full Member**

Association: **Schweizerische Gesellschaft für Muskelkranke SGMK**

Address: Kanzleistrasse 80
8004 Zürich
Switzerland

Contact: Franzika Mattes

Tel: +41 44 245 80 30

Fax: +41 44 245 80 31

Email: info@muskelkrank.ch

Website: www.muskelkrank.ch

Region: German speaking, Rhaeto-Romanic and Italian parts of Switzerland

Founded: Switzerland

- Activities:
- 🌐 Raise awareness of neuromuscular disorders
 - 🌐 Information on disease and related problems to patients, families, the public and specialists
 - 🌐 Welfare assistance
 - 🌐 The setup of neuromuscular centres in the covered region
 - 🌐 Newsletter for members three times a year

- 🌐 Special information services for ALS/MND patients and families concerning care, rehabilitation, social insurances and all forms of help in daily life
- 🌐 Set up and support of self-help groups, especially for people with ALS/MND
- 🌐 Organisation of summer and computer holiday camps for children and adults with neuromuscular diseases
- 🌐 Training for carers
- 🌐 Financial help in case of need

Status: **Full Member**

SERBIA

Association: **Yugoslav MND Association**

Address: Dr. Subotica br.6
11000 Belgrade
Serbia

Contact: Dr Zorica Stevic

Tel: +38 11 268 2988

Fax: +38 11 268 2988

Email: zsmnd.yu@sezampro.yu

Region: Serbia

Founded: June 1997

Branches: 2

- Activities:
- 🌐 The double blind clinical trial of a new agent, Alsemet, developed by the pharmaceutical company Fermin-Senta started in May 1997 with 40 patients. Alsemet administered from 1998 to 2001 with 110 ALS patients.
 - 🌐 Obtaining legal authority for the routine clinical use of riluzole from 1997 to present
 - 🌐 Completing adequate information material and distributing it to members
 - 🌐 Completing and obtaining an application for formal membership of the International Alliance of ALS/MND Associations
 - 🌐 Preparing the next meeting of the Yugoslav MND Association to discuss and solve current problems
 - 🌐 Dealing with the problems of individual members

Status: **Full Member**

TAIWAN

Association: **Taiwan Motor Neuron Disease Association**

Address: 16F Chung-Chen Building (Headquarter)
201 Shih-Pai Road, Section 2
Pei-Tou District
Taipei
Taiwan 11217

Contact: Dr Tsui-Lieh Hsu, President
Professor Ching Piao Tsai, Alliance Representative

Tel: +886 2 2820 1357










Fax: +886 2 2820 1431

Email: mnda2874@ms39.hinet.net

Website: www.mnda.org.tw

Region: Taiwan

Founded: October 1996

- Activities:
-  To promote the patient's willingness to use hospice care, even those who do not choose to prolong their lives by using a ventilator in the advanced stage of the disease
 -  To cooperate with academic research projects for developing useful communication tools such as an eye-tracking device for ALS patients
 -  To stimulate volunteerism and organise a training course for volunteers who will be able to assist ALS patient families directly or through telephone consultation
 -  To increase the awareness of ALS disease in our society
 -  To publish a second edition of the ALS Handbook, which will include disease awareness, medical care, psychological adjustments and social resources
 -  To distribute our bi-annual ALS magazine to members, ALS patients and their families
 -  To organise workshops and seminars focusing on general medical and caring skills for ALS patients and families
 -  To produce videotapes and other instructional materials on general medical care and guidance for ALS patients
 -  To expand the requirements for home care

Status: **Full Member**

TURKEY

Association: **Association of Neuromuscular Disorders**

Address: Hatboyu cad, 12
Yesilköy – Istanbul
Turkey

Contact: Professor Coskun Özdemir, President

Tel: +90 212 5730975/+90 212 6636553

Fax: +90 212 6630168














Email: info@kashastalıkları.org.tr

Email: Coskuno@superonline (Professor Coskun Ozdemir)

Website: www.kashastalıkları.org.tr

Region: Turkey

Founded 1978

- Activities
-  Publication of Periodic Journals
 -  Booklets
 -  Correspondence
 -  Seminars
 -  Courses
 -  Supporting drug trails
 -  Annual National Meeting on Neuromuscular Disorders
 -  Participating in International activities
 -  Support for respiratory difficulties in conjunction with Neuromuscular Division of Medical School of Istanbul University
 -  Rehabilitation facilities (two rehabilitation centers for neuromuscular disorders in Istanbul)
 -  Meetings related to ALS/MND with special emphasis on management for caregivers
 -  Recreation
 -  Social Activities

- 🌐 Providing wheelchairs, respirators and medicines
- 🌐 Home visits, nursing care (started Istanbul 2002)

Status: **Full Member**

Association: **ALS-MNH Dernegi (ALS-MND Association)**

Address: 7-8 Kisim Villalar
Afet Yonetim Merkezi Arkasi
Atakoy – Istanbul
Turkey

Contact: Anil Erk Yilmaz
Dr Alpher Kaya

Tel: +90 212 559 59 19
Fax: +90 212 559 44 84

Email: bilgi@als.org.tr dralperkaya@superonline.com
Website: www.als.org.tr

Region: Turkey
Founded: 2001

- Activities:
- 🌐 The objectives and activities of the ALS-MND Association cover all the area related with ALS/MND patients. The association aims at contributing to the prevention of ALS/MND; rehabilitation of patients; improvement of their life qualities, and social conditions and relationships; amelioration of basis and clinical studies, medical and surgical approaches, and clinical practices. Working in collaboration with related foundations and groups, the association deals with numerous issues by:
 - 🌐 Organising congresses, conferences, seminars, training programmes, symposiums and scientific, executive and social meetings
 - 🌐 Communicating with ALS/MND patients via the media
 - 🌐 Building a library where members can benefit from various sources in Turkish and foreign languages
 - 🌐 Publishing scientific, social and technical books, magazines, bulletins and leaflets to instruct professionals and patients, and create public awareness.
 - 🌐 Supporting scientific research and development studies: organising scientific contests; providing scholarships
 - 🌐 Organising sports tournaments and other social activities to raise funding
 - 🌐 Building a strong communication bond between ALS/MND patients

Status: **Full Member**

UNITED STATES OF AMERICA

Association: **Les Turner ALS Foundation Ltd**

Address: 5550 West Touhy Avenue, Suite 302
Skokie, Illinois 60077
USA

Contact: Wendy Abrams, Executive Director

Tel: +1 847 679 3311

Toll Free: 888-ALS-1107

Fax: +1 847 679 9109

Email: wendy@lesturnerals.org

Website: www.lesturnerals.org

Region: Patient clinic and research lab at Northwestern University, The Feinberg School of Medicine, Chicago, Illinois, USA. Information and referral for all areas.

Founded: 1977

Activities: Les Turner ALS Foundation services include the Lois Insolia ALS Center and the Les Turner ALS Research Laboratory at Northwestern, Chicago, IL, USA. Professionals on staff at the Lois Insolia Center include three neurologists, a pulmonologist, clinic co-coordinator, home liaison nurse, social worker, occupation therapist, drug study coordinator, genetic counselor and speech pathologist. The Les Turner ALS Research Laboratory is under the direction of Dr. Teepu Siddique and research is focusing on the genetics of ALS. Other services include support group meetings, loan bank of augmentative communication equipment, grant programs to assist people seen at the Lois Insolia Center with the cost of in-home respite care and durable medical equipment, home visits by our social worker and home liaison nurse and educational meetings.

Status: **Full Member**

Association: **Forbes H. Norris MDA/ALS Research Center**





Address: The California Pacific Medical Center
2324 Sacramento St
San Francisco
California 94115
USA

Contact: Dee Holden Norris, Advisory Director

Tel: +1 415 600 3604/3608
Fax: + 1 415 563 7325/+1 415 673 5184

Email: norrisd@cpmcri.org

Region: Western USA and some international visits
Founded: 1979
Branches: 8 Support Groups

Activities:  Fully comprehensive, multi disciplinary clinical patient services
 Clinical and basic science research
 Complete patient care and teaching activities
 Fundraising, education, Information and referral services

Status: **Full Member**

Association: **ALS March of Faces**

Address: 2316 Pine Ridge Road #391
Naples
FL 34109
USA

Contact: Vicki L. "Terry" Frank

Tel: +1 239 417 5458
Toll free: (877) 884 4798

Email: als@march-of-faces.org
terry@march-of-faces.org (Terry Frank)

Website: www.march-of-faces.org

Status: **Full Member**

Association: **The ALS Association**

Address: 27001 Agoura Road, Suite 150
Calabasas Hills
CA 91301-5104
USA

Contact: Jane H Gilbert, President and Chief Executive Officer
Sharon Matland, Alliance Representative

Tel: +1 818 880 9007
Fax: +1 818 880 9006

Email: smatland@alsa-national.org

Website: www.alsa.org

Region: All fifty states of the US
Founded: 1985 through a merger of the ALS Society of America and the National ALS Foundation
Chapters: 39 chapters, 5 chapters-in-organization, some chapter-affiliated support groups, 8 freestanding support groups and 20 ALSA certified ALS Centers (multidisciplinary ALS clinics)

- Activities:
- 🌐 Funds basic scientific research directed at identifying the cause of, a possible cure for and the means to prevent ALS. Conducts and supports two grant cycles per year.
 - 🌐 Is the vital link for patients and their families to information, counselling, physician referrals, in home visits, respite care and coping with the day-to-day challenges that living with ALS presents. Through its network of chapters, support groups and ALSA Centers, delivers patient services to patients, their families and caregivers at the community level.
 - 🌐 Provides education and information programs and in-services training for health care professionals.
 - 🌐 Carries out national and local public awareness and education programs through media relations, public service videos, etc., to stimulate volunteerism, scientific and health care community activism, and public support essential to fight ALS.
 - 🌐 Works with elected representatives to federal government, government agencies such as the National Institutes of Health and the Food and Drug Administration (FDA) and human service agencies to expand government support of research and to elicit programs to make treatments and care accessible and affordable for all ALS patients.

Status: **Full Member**

Association: **Communication Independence for the Neurologically Impaired, Inc (CINI)**

Address: PO Box 263
Manorville
NY 11949
USA

Contact: Peter Strugatz, President

Tel: +1 516 465 1629
Fax: +1 516 465 3744






Email: cini@cini.org

Website: www.cini.org

Region: International

Founded: 1993

Chapters: 1

- Activities
-  International resource center for communication and swallowing for ALS/MND Patients
 -  Publication of resource guide: "Communication and swallowing solutions for the ALS/MND community: a CINI manual"
 -  Professional education
 -  Communication and support of electronic bulletin boards
 -  Website

Status: **Associate Member**

Association: **ALS Hope Foundation**

Address: 219 North Broad Street, 7th Floor
PO Box 40777
Philadelphia, PA 19107
USA

Contact: Terry Heiman-Patterson, President
Jeffrey S. Deitch, Director





Tel: + 215 551 0967

Fax: + 215 762 8634

Email: info@alshopefoundation.org

Website: www.alshopefoundation.org

Founded: 1999

- Activities:
-  Provides long-term support to basic and clinical research programs leading to a cure
 -  Provides support for research at clinical centers of excellence for the care and treatment of patients with ALS
 -  Offers support for research to promote independence of the patient
 -  Supports programs that promote patient and physician education about the ALS research and the research process

Status: **Associate Member**

Association: **ALS Therapy Development Institute**

Address: 215 First Street,
Cambridge,
MA 02142
USA

Contact: Robert Goldstein


Tel: +1 617 441 7295


Fax: +1 617 441 7299

Email: info@als.net

Website: www.als.net

Founded: 1999

Activities:  The mission of the ALS Therapy Development Institute (ALSTDI) is to develop effective therapeutics that slow or stop amyotrophic lateral sclerosis (ALS, Lou Gehrig's disease) as soon as possible. The Institute is federally registered as a non-profit organization with an annual budget of approximately \$10million, raised through grants, major gifts and grassroots fundraising

-  The ALS TDI research program is designed to:
- Identify the most promising drug targets and therapeutic compounds
 - Screen potential therapeutics in the ALS validation program
 - Overcome barriers in effective research
 - Openly share results in real time with doctors, patients, and researchers

Status: **Associate Member**

Association: **Muscular Dystrophy Association**

Address: National Advocacy Office
1025 Connecticut Avenue, NW
Suite 907
Washington, DC 20036, USA

Contact: Annie Kennedy, MDA Vice President – Advocacy


Tel: +1 202 828 8560


Fax: +1 202 828 8566


Email: akennedy@mdausa.org


Website: www.als-mda.org

Founded: 1952

Activities:  Publications:
MDA/ALS Newsmagazine
Quest Magazine
Everyday Life with ALS
A Caregivers Guide to ALS
With Hope & Courage: ALS DVD
Breathe Easy
101 Hints with Ease
Facts About ALS
Meals
Emergency Preparedness materials
MDA Services brochure
Milestones in ALS Research brochure

 Awareness/Advocacy Campaigns:
National ALS Awareness month campaign – May
ALS: Anyone’s Life Story campaign
Legislative Activities
MDA Telethon – Labor Day weekend

 Services:
225 hospital affiliated MDA clinics, 36 MDA/ALS Centers nationwide; 5 regional MDA/ALS Research Centers throughout the USA
Support Groups – over 65 ALS-specific support groups offered across the nation
Financial assistance with equipment purchases and repairs (includes purchase of wheelchairs, leg braces , and augmentative communication devices)
Durable Medical Equipment Loan Closet program – loaning lightly-used durable medical equipment items, available in all 50 states
Public Health Education – Symposium, seminars, informational displays at health fairs
Advocacy – includes a national federal, legislative, health policy effort, as well as individualized advocacy efforts with local communities of PALS

 Research Program:
MDA funds ALS research in a comprehensive range of categories:-
Basic Science, Developmental, Drug Discovery, Pre-Clinical, Human Clinical Studies, and Human Clinical Trials
MDA’s current 3-year commitment to ALS Research projects - \$24,756,209
MDA currently funds research in Belgium, Canada, Chile, France, Netherlands, United Kingdom and United States

Status: **Full Member**

Non Member Support Groups

ARGENTINA

Association: **Association Distrofia Muscular**

Address: Cordoba 5824
1414 Buenos Aires
Argentina

Contact: Dr Alberto Dubrovsky, Vice President and Medical Director

Tel: +54 114 773 1714

Fax: +54 114 9561471/+54 114 956 0120

Email: dubro@fibertel.com.ar

Association: **Capítulo Argentino de Lucha contra las Enfermedades de la Motoneurona (C.A.L.Mo.)**

Address: Tucuman 950
Piso 4 Dto
23 Buenos Aires

Contact: Marta Maldonado, Secretary

Tel/Fax: +54 114 3936753

Email: info@calmo.org.ar

Website: www.calmo.org.ar

BULGARIA

Association: **Bulgarian Neuromuscular Diseases Association**

Address: 49 Nedko vojvoda Str
Sofia 1220
Bulgaria

Contact: Violeta Antonova
Tel: +359 02 939 0449
Tel:/Fax: +359 02 936 2688
Email: banmz@dir.bg
banmz@abv.bg

CYPRUS

Association: **Cyprus Institute of Neurology and Genetics**
Address: P.O.Box 23462
1683 Nicosia
Cyprus
Contact: Theodoros Kyriakides
Tel: +357-22358600
Fax: +357-22358237
Email: theodore@cing.ac.cy
Website: www.cing.ac.cy

ISRAEL

Association: **Israel ALS/MND Association (ATLAS)**
Address: 4 Kehilat Vilna St.
47220 Ramat Hasharon
Israel
Contact: Leah Schreiber, Chairman
Tel: +972 3 540 3270
Fax: +972 3 934 1220
Email: atlasals@zahav.net.il
Website: www.atlasals.org.il

MALTA

Association: **The Malta Hospice Movement**

Address: 35 Good Shepherd Avenue
Balzan BZN 16
Malta

Contact: Joanna Depares, Services Co-ordinator

Tel: +356 21440085/6
Fax: +356 21484769

Email: hospice@vol.net.mt
Website: www.hospicemalta.org

PERU

Association: **Asociacion Peruana de Ela-Apela (Peruvian ALS Association)**

Address: Clinica Stella Maris
Av Paseo de los Andres 923
Pueblo Libre
Lima
Peru

Contact: Lucas Tafur-Burga, President

Tel: +51 1 463 6666 Ext 170
+51 1 461 6286/943-3153 (Adviser)
+51 1 247 5732

Email: luctabu@yahoo.es

ROMANIA

Association: ANHR (Asociatia Handicapatilor Neuromotor din Romania)

Address: Str. Tribunalul Dobra Nr 9
2900 Arad
Romania

Contact: Ioana Monica Antoci, President

Tel/Fax: +40 57 27 27 07

Email: ahnrom@inext.ro

RUSSIA

Association: Russian Charity ALS Foundation

Address: 127327, Komintern Str
20/2, Block 1
Moscow
Russia

Contact: Gleb N. Levitsky

Tel: +7 495 472 79 29

Email: alsrus@gmail.com