











Outline of ECTRIMS aims and activities May 2018



1. Mission and Goals

For a quarter of a century, ECTRIMS has served as Europe's and the world's largest professional organisation dedicated to the understanding and treatment of Multiple Sclerosis.

The European Committee for Treatment and Research in Multiple Sclerosis is an independent representative Europe-wide organisation devoted to MS.

MISSION

To facilitate communication, create synergies, and promote and enhance research and learning among professionals for the ultimate benefit of people affected by MS.

VISION

ECTRIMS works with researchers and clinicians of its member countries and with other organisations that share similar missions and objectives on a worldwide scale, creating networking and collaboration opportunities. The ultimate goal of ECTRIMS is to improve basic and clinical research and clinical outcomes in MS.



2. Organisation

- ECTRIMS is governed by officers, an Executive Committee, and a Council of members nominated by the national neurological or MS organisations from member European countries.
- The specific roles and responsibilities of each group are outlined in the ECTRIMS bylaws which are available on the ECTRIMS website.
- Honorary members are nominated based on their outstanding contributions to the field of MS, their support of ECTRIMS and their acknowledged international reputation in the field.







Emeritus Prof. David Miller President



Prof. Bernhard Hemmer Vice President



Prof. Maria Pia Amato Secretary General



AND RESEARCH IN MULTIPLE SCLEROSIS

Prof. Tobias Derfuss Treasurer



Prof. Mar Tintoré



Prof. Sandra Vukusic



Prof. Lou Brundin



3. ECTRIMS activities: Conference

ECTRIMS hosts the world's largest annual international conference devoted to basic and clinical research in multiple sclerosis.

Recent conference:

MSParis2017 - 7th Joint ECTRIMS-ACTRIMS Meeting

25-28 October 2017, Paris / France



Next conferences:

ECTRIMS 2018

10-12 October 2018, Berlin / Germany

ECTRIMS 2019

11-13 September 2019, Stockholm / Sweden





4. ECTRIMS activities: Summer School

2013: 25 – 27 June, Bari / Italy

Topic: "Phase IV studies: New methods in Pharmacovigilance and

Monitoring - Drug Effectiveness in Multiple Sclerosis"

2014: 25 – 27 June, Tallinn / Estonia

Topic: "Genetics in MS"

2015: 16-18 June, Nice / France

Topic: "Remyelination: from mechanisms to medicines"

2016: 28-30 June, Vienna / Austria

Topic: "Use of MR imaging in diagnosis and management of multiple

sclerosis"

2017: 13-15 June, Santiago de Compostela / Spain

Topic: "Rehabilitation and symptomatic treatment in multiple sclerosis"

2018: 25-27 June, Budapest / Hungary

Topic: "Optical coherence tomography in multiple sclerosis"

4. ECTRIMS activities: Focused Workshop



2013: 7-8 March, London / United Kingdom

Topic: "Pregnancy and Hormonal Factors in MS"

2014: 6-7 March, Lisbon / Portugal

Topic: "New Technologies in MS care"

2015: 5-6 March, Larnaca / Cyprus

Topic: "Immunology of Multiple Sclerosis – from a human point of view"

2016: 3-4 March, Florence / Italy

Topic: "Environmental modifiable risk factors for multiple sclerosis:

What have we learned, where are we headed?

2017: 9-10 March, Rome / Italy

Topic: "Advancing trial design in progressive multiple sclerosis"

2018: 1 - 2 March, Brussels / Belgium

Topic: "Aggressive MS"

4. ECTRIMS activities: Regional Teaching course



The aim is to establish local teaching courses in edge areas of Europe and other (neighbouring) parts of the world and to provide access for large groups of neurologist to high quality MS teaching.

The Teaching courses are organised by ECTRIMS Teaching Course Committee with focus on collaboration with local MS neurologist communities in one or more countries.

19-20 May 2016 St. Petersburg / Russia (with RUCTRIMS)

11 November 2016 Dubai / UAE (with MENACTRIMS)

11-12 May 2017 Vilnius / Lithuania (with Baltic MS group)

15 March 2018 Buenos Aires / Argentina (with Argentinian MS

community)

Next course in 2018:

2-3 November 2018 Curitiba / Brazil (with BCTRIMS)

4. ECTRIMS activities: Guidelines



ECTRIMS-EAN Guideline

AIM: To develop an evidence-based clinical practice guideline on the treatment of patients with multiple sclerosis

GUIDELINE WORKING GROUP

Steering Committee: Chair & Co-Chair: Xavier Montalban & Ralf Gold

Members (in alphabetical order):

Maria Pia Amato, Michel Clanet, Giancarlo Comi, Tobias Derfuss, Franz Fazekas, Bernhard Hemmer, Hans-Peter Hartung, Eva Havrdova, Ludwig Kappos, Roland Liblau, Catherine Lubetzki, David Miller, Thomas Olsson, Susana Otero, Aksel Siva, Chris Selmaj, Per Soelberg Sørensen, Alan Thompson, Heinz Wiendl

First presentation of recommendations: ECTRIMS 2016 Late Breaking News

Publication of guideline: 20 January 2018

4. ECTRIMS activities: Fellowship programmes



1. ECTRIMS Postdoctoral Research Fellowship Exchange Programme

(Several fellowships per year for young neuroscientists to facilitate their training in MS basic, clinical or applied research)

24 fellows supported since 2007 (incl. 4 new awarded fellows in 2017)

2. ECTRIMS-MAGNIMS Fellowship Programme in Magnetic Resonance Imaging in Multiple Sclerosis (Several fellowships per year for young European researchers to facilitate their training in the application of MR studies to MS)

15 fellows supported since 2009 (incl. 2 new fellows in 2017)

3. ECTRIMS Clinical Training Fellowship Programme

(to provide the opportunity to learn the latest techniques in MS management and care in European MS clinic - priority given to candidates from developing countries)

12 fellows supported since 2012 (incl. 3 new awarded fellows in 2017)

- ECTRIMS Multiple Sclerosis Nurse Training Fellowship Programmes (2 or more fellowships per year for European nurses to obtain additional expertise in MS management and care)
 3 fellows supported since 2014 (incl. 1 new awarded fellow in 2017)
- → <u>NEW</u>: 2 types of programmes (comprehensive nurse training; short-term, flexible specialized MS nurse training
- **MSIF-ECTRIMS McDonald Fellowship** (1 fellowship per year for young researchers from emerging countries to enable the recipient to travel to an established research institution to work with leading researches in the field of MS.

2 fellows supported since 2016 (incl. 1 new awarded fellow in 2017)

5. Partnerships



- ECTRIMS aims at <u>strengthening cooperation</u> with organizations which share similar missions and objectives
- To this end, ECTRIMS collaborates with the International Advisory Committee on Clinical Trials in Multiple Sclerosis, the European School of Neuroimmunology (ESNI), the European Charcot Foundation (ECF), the European Academy of Neurology (EAN), Magnetic Resonance in Multiple Sclerosis (MAGNIMS), the Multiple Sclerosis International Federation (MSIF), International MS Cognition Society (IMSCOGS), Rehabilitation in MS (RIMS), European MS Platform (EMSP), European Medicines Agency (EMA)
- ECTRIMS provides financial support to some of these organisations or initiatives, e. g. ESNI Summer School, joint fellowship programme with MAGNIMS and MSIF, projects with the International Advisory Committee on Clinical Trials in MS (e. g. comorbidities project), EMSP (MS Nurse PRO education programme)

5. Partnerships



- The European Medicines Agency (EMA) engages with a network of over twenty-five eligible organisations ensuring that the needs and concerns of a wide range of healthcare professionals across Europe are represented via direct contact with the EMA.
- ECTRIMS complies with the definition of healthcare professionals' organisations, fulfils all the necessary criteria and belongs since beginning this year to the EMA network.



5. Partnerships



Cooperation with other Multiple Sclerosis societies

Meeting of the ECTRIMS Executive Committee and the following societies during ECTRIMS 2015, 2016 and 2017:

- ACTRIMS
- **BCTRIMS**

> PACTRIMS

LACTRIMS

> RUCTRIMS

MENACTRIMS

> Iranian MS Society

> MSIF

<u>Signing of Memorandum of Understanding</u>, strengthen cooperation with organisations which share similar missions and objectives, discuss possible fields of cooperation, synergies, alignment of activities etc.





- 1. Mission and goals
- 2. Organisation
- 3. Conference
- 4. Activities
- 5. Partnerships



1. Mission and Goals

GOALS

- To support and promote basic and clinical research in MS in Europe and liaise with other related organisations on a worldwide scale;
- To support education and teaching opportunities for professionals that enhance their ability to delivery quality clinical care;
- To act as representative of the MS research community in its member countries;
- To be actively involved in coordinating initiatives in research and clinical care both in Europe and worldwide;
- To organise annual congresses;
- To organise workshops and related teaching activities in the field of MS;
- To initiate, support or endorse European activities of outstanding relevance to MS;
- To encourage young researchers in the field of MS by promoting learning, training and exchange programs.