



# The International MS Visual System Consortium

## - Charter -

October 29, 2015

### 1 Goals of the consortium

The goal of IMSVISUAL is to improve care, research and education in multiple sclerosis (MS) and other neuroinflammatory disorders by advancing our understanding of the visual system. Specifically, IMSVISUAL's goals are:

1. To improve patient care in regard to visual symptoms in MS and other neuroinflammatory disorders
2. To promote and foster research of the visual system for the purpose of disease discovery in order to further our understanding of disease mechanisms in MS and other neuroinflammatory disorders
3. To establish the visual system as a model within which to monitor neurodegeneration and disease progression, as well as neuroregeneration and neuroplasticity in MS and other neuroinflammatory disorders, both for the purpose of tracking patients, as well as outcome measures in clinical trials.
4. To improve upon existing, as well as develop new techniques for assessing the visual system.

### 2 Structure of the consortium

#### 2.1 Members

Membership is open to anyone with a proven interest in the consortium's goals. Membership is free of cost and can be terminated any time. Membership will enable participation in IMSVISUAL activities. Members can be elected into the board of directors and can participate in the working committee.

#### 2.2 Board of directors

The board of directors consists of a small, stable group of not more than five highly experienced individuals that work well with one another and that can be trusted to do what is in the best interest of progressing visual system research in multiple sclerosis (MS). The board of directors is responsible for the inception of the consortium, establishing the long-term goals, the general tone and character of the consortium, broadly overseeing the general running & management of the consortium, and resolving disputes. The board of directors will appoint a working committee to execute the general management of the consortium. The board of directors, together with the working committee will be responsible for the procurement of funding in order to establish and maintain the consortium. The board of directors will meet ad hoc and coordinate their work regularly via teleconferences and in person. Members of the board of directors will

serve a two-year term that is renewable. The number of terms an individual can serve is not limited. All consortium members can become members of the board of directors by majority vote every two years.

### 2.3 Working committee

The working committee is responsible for executing the majority of organizational work in the consortium and is involved in strategic decisions. Together with the board of directors, it will be their duty to procure funding to enable the establishment and maintenance of the consortium. The working committee will coordinate their work regularly via teleconferences and in person.

Consortium members participate in the working committee by taking over responsibility for regular organizational duties of the consortium. The board of directors will appoint members to the working committee based on the committee's organizational needs and members' suggestions.

### 2.4 Steering committee

The board of directors and the working committee together form the steering committee. The steering committee will coordinate research activities of the consortium and review internal project proposals from consortium members.

### 2.5 Scientific Advisory Board

The scientific advisory board of the consortium consists of not more than 20 experienced individuals with a proven commitment to MS research and care or vision sciences. The scientific advisory board serves as an independent source of advice to the consortium and its members in order to ensure that the consortium remains a dynamic, forward-thinking, and evolving entity. The scientific advisory board will support the steering committee in reviewing internal consortium proposals.

Appointments to the scientific advisory board are the decision of the steering committee. Members of the scientific advisory board will serve a two-year term that is renewable. The number of terms an individual can serve is not limited.

## **3 Activities of the consortium**

### 3.1 Shared data repositories

IMSVISUAL promotes the creation of a shared data repositories, including, but not limited to, demographic, clinical, optical coherence tomography (OCT), magnetic resonance imaging (MRI), visual electrophysiology, genetic, diagnostic, therapeutic, immunologic, and cerebrospinal fluid (CSF) data. Shared repositories will allow pooling of data from across multiple centers, in order to leverage the power of the consortium for the purpose of studying the visual system.

All members can access central repositories by submitting formal project proposals to the consortium. All proposals will be carefully reviewed and discussed by the steering

committee, and either approved or declined by consensus. In circumstances where a consensus cannot be arrived, the scientific advisory board will be consulted.

### 3.2 Specialty groups

IMSVISUAL promotes creation of specialty groups to pursue specific and specialized projects. All members can participate in specialty groups by submitting formal project proposals to the consortium. The steering committee will review proposals and establish specialty groups based on the consortiums goals and needs.

Participation in specialty groups is open to all members. The board of directors will appoint two chairs to each specialty group. Specialty groups will meet regularly via teleconference or in person.

### 3.3 Meetings

IMSVISUAL holds recurrent meetings at least twice a year in order to regularly review the progress of the consortium towards meeting its goals, to enable consortium members to provide updates on their research progress, to identify and overcome barriers towards progress, to ensure standards across the consortium are being maintained at the highest level, and to offer a platform of education that is open to anyone with interest to attend, including those that are not members of the consortium.

### 3.4 Guidelines

IMSVISUAL promotes establishment of guidelines for visual system assessment (clinical, structural, and functional) in order to ensure that data acquired across all sites within the consortium are of optimized quality and consistent across sites. These guidelines will also serve to be instructive for sites that are not part of the consortium and will be available for download for everyone from website.

### 3.5 Publications

IMSVISUAL promotes publications by the consortium resulting from other activities e.g. specialty groups or shared repository data. Actively participating scientists will be named authors on these publications, followed by „on behalf of the IMSVISUAL consortium“. All members will be given the chance to review and contribute prior to submission. Contributing members will be registered by name under the consortiums name in PubMed.