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| Board Paper: Progress against indicators in 2012-16 Strategic Plan |
| Paper **20** |
| Agenda itemCEO Report (Board Meeting 20 September) |
| **From:**  Ceri Angood, Director of Programmes |
| ConsultationAll staff  |
| Signed off byPeer Baneke, CEO |
| Proposed decision: For information. |

**Paper 20**

## Introduction

This paper presents a snapshot of progress made relating to the objectives and indicators that were set out in MSIF’s 2012-2016 strategic plan. It differs from the CEO report because rather than describing what activities have taken place only in the time between board meetings, it looks cumulatively at what has been achieved since 2012.

**Key:**

* This symbol means we have achieved the indicator set out in the strategic plan,
* This one means we have not achieved it
* This one means we don’t know if we have achieved it because we did not or found it difficult to measure it. In some cases we provide a proxy measure instead of the one outlined in the strategic plan.

**Research Aim:**

Together with our Members active in research, to facilitate, coordinate and lead international cooperation and collaborative initiatives to better understand the nature of MS, to develop better treatment and rehabilitation of people with MS and inform relevant communication and advocacy initiatives.

**Objective 1: Substantial progress in the key fields of paediatric MS, progressive MS, stem cells and databases/registries.**

**How have we done?** MSIF and its members have brought renewed focus and attention of the global research community to progressive MS through the establishment of the Progressive MS Alliance. We have contributed funds to, but await the results of, a large international trial on stem cells (MESEMS). We have made limited progress in the area of database/registries but highlight this as an area of focus for the new strategy. In 2016 we adjusted our approach on Paediatric MS and contributed to progress through sharing of information.

**Progress on indicators that were in the 2012-16 strategic plan:**

* Position paper published in 2012. Progressive MS Alliance, of which MSIF is a founding and managing member, established in 2014.
* 3 major scientific meetings held (the target was 1) on Progressive MS: 2014 (Milan), 2015 (Boston), 2016 (San Francisco).
* The International Pediatric Study Group did not acquire a project grant or publish an international study on environmental factors in paediatric MS.
* We did not measure satisfaction ratings of MSIF coordination from members of the International Paediatric MS Study Group (the target was to get high satisfaction). As proxy, when surveyed in 2013, 91% of the IPMSSG reconfirmed their membership.

**2. Broadened involvement in MS research by supporting new entrants to MS research, in particular from emerging countries, and enhanced support of people affected by MS.**

**How have we done?** From 2012-2016 MSIF supported 60 young researchers from 26 countries, 80% of whom were from emerging countries, to do research in MS. Many have now returned and are contributing to MS research and care in their own countries.

* Over 50 papers (the target was 5) have been published in high quality journals by MSIF fellows/grantees. 12 Alumni (the target was 10) have been involved in establishing or volunteering for their national MS organisation.

**3. Increased coordination of research by MSIF, its Members and scientific community.**

**How have we done?** We have contributed to the establishment of the Progressive MS Alliance. The research staff network was established in 2016, with a meeting we called in London to explore collaboration.

**4. Increased strategic targeting of Member and MSIF Research Funding.**

**How have we done?**

* 14 members are participating in pooling funds (the target was 10) for the Alliance. 7 members have also been involved in pooling funds for paediatric MS meetings etc.

**Capacity building and emerging countries Aim:**

Initiate, support and encourage the development of new MS organisations. Support emerging structures and stimulate and support existing national MS organisations in their work to improve the quality of life of people affected by MS.

**Objective 1: New MS organisations in countries without one**

**How have we done?** In China, a pilot project for this objective, whilst there is growing engagement, there is not yet a self-reliant national organisation. However, we can celebrate the strengthening of a national network of people motivated and active in MS awareness raising, information provision and professional and peer support. We have produced 5 issues of *Listen* magazine in Chinese, with a total of 2,500 printed copies being produced in addition to online availability, and in 2016 our small grants enabled five MS community-led World MS Day events to take place in Beijing, Shanghai and Jinzhou.

**Progress on indicators that were in the 2012-16 strategic plan:**

* There are several groups in China who are involved in MSIF’s projects and programmes including World MS Day. Whilst sustainability is an issue, one of the groups has a regular volunteer whose living costs are covered by a local funder.

**2. Stronger MS organisations in emerging countries**

**How have we done?** In the Arab region, MSIF has helped MS Care (Egypt) and ALSEP (Lebanon) to identify areas of need for organisational development, then in producing their first strategic and fundraising plans as well as building their volunteers’ capacity in planning, fundraising, communication and psychological support provision. The following quotes provide evidence of this:

*‘(The) MSIF capacity building program was the agent that powers our purpose and direction.*

*The continuity of this program throughout three years helped ALSEP to fulfill its mission and sustain itself. We became able to articulate value and tie strategy to mission and society capacity. It also allowed us to drive our mission forward, meet our goals and have a real impact on the community we serve.’*  Wissam [Al Hajj](https://eu3.salesforce.com/_ui/search/logging/SearchClickLoggingServlet?searchType=2&sen=00O&str=wissam&clkLogFlag=1&clkRecordId=00320000016uxg7&clkQueryGuid=plj4xvgp2fw&clkCount=3&clkRank=2&clkBucketRank=2&clkIdHash=f560959bf1d3217d85125915cfbd4124&clkNumResultsForEntityBeforeDb=3&clkPageNum=0&clkNumResultsPerPage=25&clkFilter=&clkSort=&clkIsTagging=false&clkEntityName=Contact&retURL=%2F00320000016uxg7%3FsrPos%3D1%26srKp%3D003&), Board member, ALSEP, Lebanon

*‘I’m not stressing on tangible results though they are very important like increasing treatments coverage from 25% in 2013 to 100% at present , increasing numbers of people served from 1000 to 3000 , three folds the amount of money in the bank account…, percentage of money from pharma from 100 % to 30%... Numbers of members from 50 to 300. The most important achievement of all is the change happened in the culture of the society. Now we know how right things are done right. Now we work according to what everybody else around the world is working. Now we speak the same language. This experience turned our society to a miniature of any big society. ‘*

*Mai Sharawy, Board member, MS Care Egypt*

The results from MSIF’s 2013-15 regional evaluation show positive outcomes with the activities contributing to an increase in communication and exchange of experiences, high levels of learning and adoption of new ideas by MS organisations. For example:

*‘AMMASEP was able to improve the quality of its work and dealing with others particularly with funders and attracting volunteers.’*  Rachida [Tenouri](https://eu3.salesforce.com/0032000000iGkxV?srPos=0&srKp=003), President, *AMMASEP, Morocco*

**Progress on indicators that were in the 2012-16 strategic plan:**

* 3 MS organisations (the target was 2) from the Arabic-speaking region have reached MSIF Associate Membership standard.
* In one country-focused capacity building project (MS Care in Egypt), the income has grown by 190%[[1]](#footnote-1) (the target was 30%) in the period from 2013-2015.
* 6 twinning (target was 6) partnerships (or modest exchanges) have taken place

**3. A competent and professional membership**

**How have we done?** An increase in organisations reaching membership status indicates that there is an increase in reaching a professional standard or organisation – upholding policies such as relations with the health care industry etc.

Evaluation forms from best practice sharing events such as theCEO meetings, Fundraising workshop indicate we are providing opportunities for member organisations and their staff to try new things, learn from and support others and develop professional expertise. We of course don’t know all of the spontaneous exchanges from which members benefit, such as Canada hosting the new CEO of the French MS Society.

We know some members face big financial and leadership challenges. We also know the challenge of competition between organisations at national level but have fantastic examples of members in France and Spain coming together on common platforms such as the Progressive MS Alliance and Living with MS day respectively.

* Over 60% of MSIF’s member’s attended the World Conference in Berlin

**4. Increased engagement with the wider MS community**

**How have we done?** In the period 2012-16, MSIF has built relationships with 25 new MS groups and organisations in non-member countries, and has begun to engage with a further 21. This has enabled MSIF to inform, advise and involve an additional 20 countries, territories or states in the MS movement. We observe that World MS Day is often the first activity that mobilises them.

Since 2012, the MSIF movement has grown by 21%.[[2]](#footnote-2) Simultaneously, we havedeveloped newpartnerships with the TRIMS that offer new funding models and means of engagement with the wider MS community, our relationship and collaborations with EMSP is strong.

**Advocacy and Campaigning Aim:**

Raise public awareness and understanding of MS by uniting the global MS movement through campaigning and advocate for the interests and rights of people affected by MS, in order to improve their quality of life.

**Objective 1: Increased global awareness of MS amongst the public and policy makers**

**How have we done?** The new World MS Day strategy reflects all that we have learned about World MS Day since 2012. World MS Day isn’t just about awareness raising (either by MSIF or members), it is a mobilising tool which MS organisations can use to further their own objectives and thus the global MS movement. It is extremely difficult (and expensive) for MSIF to measure awareness changes at a national level.

The continued growth in World MS Day participation shows that it is useful and valuable to members, this has also been reflected in qualitative evidence from member organisations collected in annual evaluations. As an international campaign, World MS Day builds global solidarity, but also gives MS organisations useful leverage for advocacy. For example in 2016 the Uruguayan Palace of Laws was illuminated orange for World MS Day, and Magdalena from the society said: “*World MS Day has helped year after year to increase our visibility and raised awareness in Uruguay as well as in Uruguayan authorities, so we think it has become one of EMUR’s best strengths. The Palace of the Laws illuminated in orange on WMSDay2016 was like a dream came true. We know that 2000 persons with MS are not a great amount of votes for politicians, so we think MS is a genuine concern for our authorities and we hope this is a starting point for better policies concerning this matter*.”

 **Progress on indicators that were in the 2012-16 strategic plan:**

* For the last two years 100% of MSIF’s member organisations (full members, associate members and supporting organisations) have taken part in World MS Day, compared to 80% of members in 2012. In 2016 there were events in 89 countries compared to 66 in 2012. 80% of members ran a national activity in 2016 compared to 51% in 2012.
* The poll we conducted did not find there had been a 10% increase in awareness of MS in 5 selected countries (Argentina, Egypt, India, Ireland and Estonia).

**2: Increased policy impact and opportunities for MS organisations through international epidemiological and socio economic comparative research and international action**

**How have we done?** The socio-economic research we have produced in this period (Atlas of MS, Employment report etc) has supported MS organisations’ advocacy impact. Between October 2013 and August 2016, around 43,000, queries have been made on the Atlas of MS database, the majority of these have been related to the epidemiology of MS. The MS Society of Romania used Atlas data in a 2013 campaign to increase access to treatments. The Portuguese, Dutch, Spanish, Hungarian and Italian MS Societies had the report translated so they could use it to raise awareness and 79% of respondents to MSIF’s 2013 communications survey said that the comparative data that MSIF produces on epidemiology or socioeconomic trends, is either fairly or very important to them.

In addition, MS organisations use World MS Day and our capacity building work to support their efforts to influence policy, with some success, for example, MSIF members in Poland and Egypt have contributed to securing increased access to treatments.

**Progress on indicators that were in the 2012-16 strategic plan:**

* The Atlas of MS was updated in 2013 and provides up-to-date epidemiological data from 12 more countries than the 2008 edition.: We are unable to track how many times the 2013 Atlas itself has been cited but the article we wrote about the Atlas published in *Neurology* has been cited in 46 publications (the target was 15) and the figure of 2.3 million people with MS, quoted in many more..

**Information and communications aim:**

Enhance and complement (particularly emerging) MS organisations’ efforts to provide information which meets the needs of people affected by MS. Be a resource for people affected by MS who do not have access to an MS organisation

**Objective 1: Promote internal communications within the MS movement – so the movement functions more effectively**

**How have we done?** We have promoted internal communication through convening two in-person meetings per year, which are highly valued by our membership. For example, 76% attendees for the meeting in Dublin strongly agreed it was worth their money and time to attend. We organised regional events to share best practice (such Jordon, at MENACTIRMS in 2016), conducted webinars and live online events on topics such as progressive MS and working with the media and provided regular CEO email updates and newsletters (noting that these reach beyond an internal audience).

Establishing the research staff network contributes to this objective, as does the various email lists we have for communications and fundraising staff. Similarly, the introduction of various work groups to guide important projects, and as part of the new strategy development process, not only promotes internal communication but strengthens relationships and builds capacity and engagement whilst achieving common objectives.

MSIF has coordinated the production of 14 issues of the quarterly e-newsletter Tawasol for the Arabic speaking region since 2013. Tawasol was initially created to facilitate communication and experience sharing between MS organisations, but in addition, our evaluation found that the recipient organisations also use it to document activities, communicate their work to donors and be held accountable to people affected by MS.

Lastly, we tried to get members to use an MSIF intranet (member’s area) but this wasn’t successful. We will build on all this in the next strategic period.

* Twitter and Facebook member engagement rates have steadily increased over time.

**2. Produce and translate information primarily for MS organisations to adapt and use – so MS organisations (especially the less well-resourced) have access to the latest global information, and so costs and duplication within the MS movement are minimised**

**How have we done?** Since 2012 we have produced and translated several publications and many newsletters that MS organisations have adapted and used. A recent example is **‘**Childhood MS: a guide for parents’, which was shared with members at the beginning of July 2016. It was made available in English, Spanish and Arabic, and many of our members are translating it further (Polish, Czech, French, Dutch/Flemish, Norwegian and Danish).

MS in Focus was regularly translated by members including Spain, the Netherlands, Italy and others. The total number of downloads for all editions of MS in Focus since 2012 is over 30,000. MS organisations regularly reuse articles from research news by sharing them with their own audiences, in their own publications and on their social media pages.

**Progress on indicators that were in the 2012-16 strategic plan:**

* Reuse of MSIF content by members: members from Italy, Netherlands, Spain and India, among others, regularly reuse and repurpose the information we provide to reach their own audiences
* The survey of Jan 2014 revealed 42% of members who responded used MS in Focus ‘sometimes ‘or ‘a lot (the target was 30%’).
1. **Protect and enhance the MSIF brand**

**How have we done?** As an indication of how MSIF is perceived,83% of respondents to MSIF’s 2013 communications survey agreed (either strongly or slightly) that the information MSIF produces can be trusted.The fact that many MS organisations, especially the smaller, less-well-resourced ones, regularly use the MSIF logo suggests a high level of kudos associated with it.

In 2014 we refreshed MSIF’s logo for digital visibility and in 2015 we facilitated a discussion at the CEO advisory group meeting to explore the appetite for global branding e.g. disease branding, kitemark etc. It was concluded that there are sufficient branding efforts – World MS Day, Kiss Goodbye to MS - and agreed to introduce a new variation of the MSIF logo for member (full, associate and supporting) use only to indicate their key role in the Federation.

1. **Support MSIF research, capacity building, advocacy and fundraising.**

**How have we done?**

* MSIF’s e-newsletters and social media reach 97%[[3]](#footnote-3) more people than in 2011 (the target was 50%).
* Research News newsletter is produced every month (in collaboration with the Institute of Neurology) and sent to over 17,000 subscribers. Open rates are consistently above the industry average.
* Two members of MSIF staff sit on the Progressive MS Alliance communications team ensuring materials and messaging produced are of international relevance.

In addition, the work to support the fundraising department’s pilot for digital fundraising was an excellent example of cross-organisation coordination.

**Fundraising Aim:**

Grow the fundraising income of the MS movement to improve the quality of life for all people affected by MS.

**Outcome 1: A more coherent understanding of Fundraising as part of an international movement, cooperation, collaboration and increased working together across the membership.**

We have held 3 highly successful and well attended fundraising workshops. 35 members participated in year one, 43 in year two, and at the time of writing similar numbers are predicted for 2016. These fundraising workshops are an important platform for helping members to learn from each other and make decisions on potential new channels. The informal and formal feedback has been very positive and although it is difficult to attribute specific actions to the Workshops several countries have adopted new channels, tools and processes following the workshops.

One example is that they have paved the way to roll out Kiss Goodbye to MS as a global fundraising campaign. This is the biggest ever international fundraising collaboration in the MS movement. With eight countries taking part in 2016 and 12 or 13 in 2017 this represents a new chapter for the Federation.

**2. Grow & diversify income of MSIF Secretariat - A more balanced fundraising portfolio, an increase in oncome which will allow diversification of Vanneau funding and growth in MSIF’s international programmes and increase in reserves.**

**How have we done?** Voluntary (not including membership fees or Vanneau) income for MSIF has grown by 48% since 2013, against a target of 30%. The major positive of this is that we have been able to fund more programmes whilst also reducing our take from the Vanneau Trust to make it more sustainable.

The downside is that nearly all of this income is from the pharmaceutical industry, which takes us near to 45% of income from that channel. However, to mitigate that we have ensured that all of our programmes are multi-stakeholder funded. We have also diversified from three significant pharmaceutical funders to six, and discussions with three more. This will enable us to continue reducing the funding from each company, while protecting income and reducing risk in the volatile pharmaceutical sector.

Having tested digital and low-level foundations we are now exploring high-value foundations, corporate and major donor prospects, some independently and some in partnership with members. If we can increase these channels we can diversify away from the pharma sector and balance our portfolio better.

* MSIF has increased voluntary income (not including membership or Vanneau) by 48% (the target was 30%) from £530,000 in 2013 to around £785,000 in 2016.

**3. Grow and diversify income of the MSIF membership – Global Fundraising strategy**

**Progress on indicators that were in the 2012-16 strategic plan:**

* It is difficult to tell if we have increased funding for MS research. The terminology and way people record income vary so much that it is very difficult to provide useful comparative data.
* We have evidence of more societies funding research: 2 of the 14 members of the Progressive MS Alliance have never previously funded international research.
* Several MSIF Members are expanding fundraising channels (target was 5), but it is hard to gauge exactly how much impact can be attributed to MSIF support.
* At least 5 MSIF members (target was 5) have established new fundraising channels (e.g. started digital fundraising or event) as a result of the fundraising workshops or participating in Kiss Goodbye to MS.

**Progress against the milestones outlined in the 2012-16 Strategy**

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| **2016** | * New Strategy
* Additional income reached for MSIF
* Additional income not reached for membership
* Study into Environmental Factors in Pediatric MS not published.
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| **2015** | * 2nd International research coordination meeting
* Latin America situational analysis (additional capacity building project) starts
* Preparation of new Strategic Plan
* New World MS Day 3 year strategy
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| **2014** | * World MS Day: access to treatment + awareness survey results
* Initial preparation for Latin America programme
* Research proposal on environmental factors in pediatric MS – not funded
* Additional capacity building project postponed
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| **2013** | * Atlas of MS
* Progressive MS Meeting
* Arab Region capacity building
* World MS Day: young people
* Global Fundraising Strategy
* World MS Conference, Berlin
* 2nd International Research Coordination Meeting
* Report on environmental factors in pediatric MS not published
* 1 global corporate (non pharma) partnership not achieved
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| **2012** | * Progressive MS Collaborative starts
* Pediatric MS Seminar
* World MS Day: living with MS + baseline
* 1st global fundraising project agreed by Board: Progressive Alliance
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1. MS care income: 60,000 EGP in 2013, 89,059.70 EGP In 2014, 173,878 EGP in 2015 [↑](#footnote-ref-1)
2. Increased from 89 to 108 organisations involved: 33 members, 10 associates, 1 supporting, 46 corresponding in 2012 to 33 members, 14 associates, 3 supporting and 60 corresponding in 2016. [↑](#footnote-ref-2)
3. Taking World MS Day Facebook reach as a proxy: 50,000 in 2012, 98800 in 2016 [↑](#footnote-ref-3)