

Summary of strategic review process

- Alliance Meeting 2011
 - Draft Strategic Plan 2012 – 15 presented to members
 - Group discussion on the draft plan
 - Vision, Mission and Objectives confirmed
 - Working groups established
 - Working group review undertaken and report with recommendations submitted to board June 2012
- Alliance Meeting 2012, 2013, 2014
 - Working group reports to members on outcomes
 - Board report on key actions for following year
 - Working group discussion on actions and working group priorities for following year



GOAL:

A world free of ALS/MND

TAGLINE/BRANDING:

United in the worldwide fight against ALS/MND



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

VISION:

We will engage with our members, prospective members and other organisations to share resources globally, to advance awareness and to promote support of people living with ALS/MND worldwide



MISSION STATEMENT

Our Mission as the International Alliance of ALS/MND Associations is to encourage:

- optimal care and support for all people living with ALS/MND
- information exchange and education at an international level
- collaboration, dissemination and translation of ALS/MND research



Strategic Objectives 2012 to 2015

1. To develop the **operational structure** required to achieve our objectives
2. To develop and enhance **membership, partnerships and programs**
3. To facilitate the exchange of **information** on ALS/MND care, education and research
4. To build a **sustainable operating/funding model** for the Alliance



WG Established at Dec. 2013 Meeting	Board rep	Members
<p>Partnership: To review and develop the many facets of the Alliance's Partnership Programme, including the establishment of regional mentors, the Needs & Offers programme, the inclusion of Partnership Success Stories on the Alliance website and the application and evaluation process for providing partnership travel funding through the Alliance Support Grant.</p>	<p>Sara Feldman & Efrat Carmi</p>	<p>David Ali (Australia) Martin Burger (Switzerland) Rod Harris (Australia) Chi-Shin Hwang (Taiwan) Kathy Mitchell (Canada) Dario Ryba (Argentina) Teresa Salas (Spain) Richard Sloan (England)</p>
<p>Programs: To review, develop and enhance Alliance programmes and to develop a strategy of marketing and public relations campaigning to promote Alliance programmes, such as Global Day activities, the March of Faces and social media campaigning.</p>	<p>Carol Birks</p>	<p>Jean D'Artigues (France) Tatiana Mesquita e Silva (Brazil) Teresa Salas (Spain) Craig Stockton (Scotland) Thomas Stucki (Switzerland) Carla Yolotl (Mexico) Valerija Kozlova & Ralcovs Valerijs (Latvia)</p>
<p>Advocacy: To facilitate the exchange of information on ALS/MND care, education and research internationally and to build the Alliance's role as a global advocate in the fight against ALS/MND</p>	<p>Lindee David</p>	<p>Antje Faatz (Germany) Terry Heiman-Patterson (USA) Jodi O'Donnell (USA) Francesco Rotta (Brazil)</p>

WG Established at 2013 Meeting	Board rep	Members
<p>Income Generation To build a sustainable operating/funding model for the Alliance, to develop formal recommendations for future funding models and to facilitate fundraising and other means of income to ensure the sustainability of the Alliance.</p>	<p>Steve Bell</p>	<p>Rod Harris (Aust), Joyce Lin (Taiwan) Yen-Chu Liu (Taiwan) Kim Maginnis (USA) Josette Reugg (Switzerland) Yves Tronchon (France) Kiki Qu (Taiwan)</p>
<p>Science & Research To assist the Alliance in meeting its goal to encourage ALS/MND research collaborations and translate and disseminate relevant information and resources.</p>	<p>Bob Bestow</p>	<p>Armelle Debru (France) Rob Goldstein (ALS TDI) Loftur Altice Thorsteinsson (Iceland)</p>

Partnerships WG Report 2014

Goals	Actions	Outcomes
1. Develop the Mentorship Program	<ul style="list-style-type: none">• Establish the role of the Alliance and define the mentorship program• Investigate the funding issues• Develop process for finding the right mentors• Develop a training program• Define the reporting process	<p>By March 31 2015:</p> <ul style="list-style-type: none">• Establish board committee with co-opted members if required• Develop resources/forms/website• Identify organisational mentors• Develop reporting process<ul style="list-style-type: none">• receive quarterly reports• Annual presentation
2. Develop the Collaboration Program.	<ul style="list-style-type: none">• Establish the role of the Alliance and define the program• Consider how the traditional Needs and Offers can fit into the new structure.	<ul style="list-style-type: none">• Formalise reporting process for collaborations between existing organisations<ul style="list-style-type: none">• receive quarterly reports• Annual presentation



Programs WG Report 2014

Goals	Actions	Outcomes
<p>1: to support member associations to create and implement a <u>March of Faces programme</u> to assist with advocacy and awareness</p>	<ul style="list-style-type: none"> • Share organisations' March of Faces materials. • Develop and design a toolkit for the website • Work towards creation of a 'world of faces' 	<ol style="list-style-type: none"> 1. Resources gathered from WG members 2. Existing Country of Faces identified <ul style="list-style-type: none"> • Brazil and Scotland
<p>2. to create a coordinated Global Day campaign</p>	<ul style="list-style-type: none"> • Create Global Day campaign and guidelines • Develop key Global Day social media messages • Communicate to members • Link to giving platforms 	<ol style="list-style-type: none"> 1. One Global Team One Goal campaign initiated 2. Resources developed 3. 20 members participated 4. 100 new social media followers 5. £300 raised via EDH 6. Participation from sportspeople
<p>3. to #ShoutLoud at regular intervals throughout 2014.</p>	<ul style="list-style-type: none"> • Engage members and ALS/MND community through social media • Raise awareness of the needs of PALS • Support key aligned international awareness campaigns • Promote Alliance programs 	<p>Targeted key messages developed for each campaign:</p> <ol style="list-style-type: none"> 1. Brain Awareness Week (10-16 March 2014) 2. Global Day (21 June) 3. World Hospice and Palliative Care Day (11 October 2014) 4. International Meetings, International Day of People With Disabilities, Giving Tuesday (early December 2014)

Advocacy WG Report 2014

Goals	Actions	Outcomes
1. To engage and mobilize member associations to develop advocacy	<ul style="list-style-type: none">• Create an “advocacy toolkit” for members• Develop a process for International Alliance policy statements to be formally approved by member organization boards	
2. To have Alliance policies recognized by global health organizations and increase Alliance capacity to advocate on global initiatives	<ul style="list-style-type: none">• Review, revise and develop Policies and Position statements to ensure they are up to date, politically neutral and internationally meaningful<ol style="list-style-type: none">1. Patients Rights Policy	

Income Generation

Key Reco'dations 2013	Draft Actions	Outcomes Dec 2014
Increase subscription fees	<ul style="list-style-type: none"> • Analysis of fees currently paid • Measurement of impact of changes 	<ul style="list-style-type: none"> • New members • ncrease in subscriptions
APF and Annual Alliance meeting to run at a profit	<ul style="list-style-type: none"> • Formalise price setting mechanism • Develop and monitor cost centre budget • Develop sponsorship package 	<ul style="list-style-type: none"> • Price setting formula in place • Package developed • Sponsors secured
Establish a range of new initiatives to enhance income and ensure sustainability of the Alliance	<ul style="list-style-type: none"> • Develop a legacy/bequest giving program • Examine opportunities for start up funding for administration and CEO/ED • Develop an International donations program • Explore joint FR with other neuro groups • FR activity for members - % to the Alliance • Major events – concert/soccer match 	<ul style="list-style-type: none"> • Every day hero online giving platform • Giving Tuesday • IBC donations from members • Partnership program
Develop named specific projects to appeal to large gift funders	<ul style="list-style-type: none"> • Organisations to self identify needs • Needs based project and funding submission developed 	<ul style="list-style-type: none"> • Discussions with Biogen ALS i-hub team
Global Day fundraising for Alliance -	<ul style="list-style-type: none"> • Present idea to Alliance members • Funds directed to the Alliance for partnership projects and international development 	<ul style="list-style-type: none"> • One Global Team One Goal
Improve rationale of Alliance to broaden appeal to funders	<ul style="list-style-type: none"> • Update mission statement • Seek funding from EU etc 	

Science and Research

Key Reco'dations 2013	Draft Actions	Outcomes Dec 2014
	To assist the Alliance in meeting its goal to encourage ALS/MND research collaborations and translate and disseminate relevant information and resources.	



Board Committees 2015

Budget, Finance, Compliance and Administration		Assist the Board in the effective discharge of its responsibilities for financial management, reporting, internal controls, risk management, and the internal and external audit processes in accordance with UK and English laws regulating incorporated charities. Assist the Chairperson in developing and supporting the role and function of the Alliance Manager
Membership		Evaluate new member applications and make recommendations to the board
Alliance Support grant		Evaluate Alliance Support Grant process and requests and make recommendations to the board
Annual Meeting Program		Design the Annual meeting program, call for abstracts, review abstracts, finalise program
Nominating		Identify new board members and make recommendations to the board
Forbes Norris Award		Evaluate nominations and make recommendations to the board
Humanitarian Award		Evaluate nominations and make recommendations to the board

What should be the priorities for 2015?

Partnership and mentor program next steps – establish board committee to deliver the working group recommendations

Working Groups 2015:

1. Marketing and communications (programs)
2. Income generation
3. Advocacy
4. Research

Anything else?



Workshop - goals for 2015

Identify 1 or 2 goals for discussion, decision, delivery i.e:

1. Marketing and communications (programs)

- Ice Bucket Challenge
- Global Day <http://battleofthemountain.com/>

2. Income generation

- Funding for partnership program
- Sponsorship

3. Advocacy

- Identify policy imperatives
- Be a stronger global advocate for ALS/MND

4. Research

- Promote sharing of registry data internationally. See <http://www.treat-nmd.eu/resources/patient-registries/global-registries/introduction/>
- TriCALS <https://www.tricals.org> linking pw ALS/MND with clinical trials and Pharma's
- Support meeting to update and renew ALS Clinical Trial Guidelines.

