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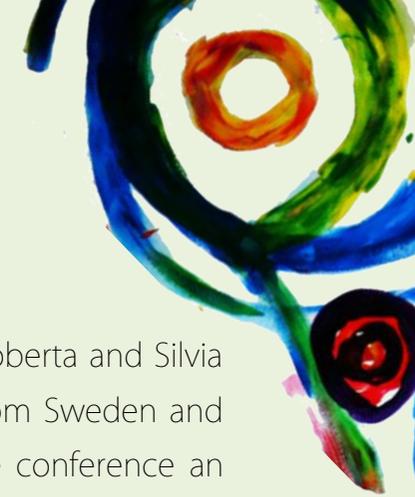
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Special gratitude goes to the moderators: Camille from France, Emma from Ireland, Ann from Poland, Inès from Spain and Shana from UK.

Last but not least, EMSP would like to express its gratitude to all sponsors and partners for their continued commitment to support EMSP. THANKS to everybody who made this Youth Congress possible and a great experience!





## INTRODUCTION

*By Shana from United Kingdom, chairwoman of the EMSP Youth Congress 2011*

The EMSP Youth Congress is a really unique opportunity to discuss the specific needs and requirements of Young People with MS (YPwMS), and to share information about projects and services in different countries across Europe.

Following the great success of the first Youth Congress in 2010, the second EMSP Youth Congress took place on May 12<sup>th</sup> 2011 in Brussels. There were twenty participants from fourteen European countries: Belgium, Czech Republic, Estonia, France, Ireland, Italy, Latvia, Netherland, Norway, Poland, Romania, Spain, Sweden and UK.

This year, 2011, there were four main topics discussed during the Youth Congress:

- Information about MS.

Discussion took place around how young people access information about MS in different countries. There was debate

around the kind of information that YPwMS are looking for and the difficulties YPwMS face when looking for information.

- YPwMS and MS Societies.

The final discussion table focused on how each Country's MS Society involved YPwMS. There was further discussion about what YPwMS expected and actually needed from their MS Society.

- Networking for Young People with MS.

Discussions took place about the importance of networking through both social media and face to face interaction for YPwMS. Discussions included how to set up such networks, how to maintain and monitor these networks and what the networks could achieve.

- Fundraising by YPwMS.

Discussions took place about the kind of activities that YPwMS want and how these should be financially supported. There

was debate about how and to what extent the MS Society could be involved.

It is very important that the information and ideas shared at the Youth Congress are reported back to the National MS Societies to directly influence their work with young people in the future.

The Youth Congress is an excellent starting point to come together in one place to share information, but participants all believed that there would be great benefit from ongoing support and discussion. There needs to be an effective way of communicating as a group throughout the year so participants can continue the excellent discussions and idea sharing started at the EMSP Youth Congress.

The 2011 EMSP Youth Congress was a great success and a springboard for many further discussions and initiatives in the participant's respective countries. Everyone is looking forward to meeting again next year.





## INFORMATION AND YOUNG PEOPLE WITH MS

*Emma from Ireland*

### Where to get information?

Primary sources for information for YPwMS include **doctors, neurologists and other healthcare professionals**. In Norway, a two-day course for newly diagnosed people includes participation by nurses, doctors and neurologists. People can bring a friend or their partner. This multi-disciplinary approach provides a means for YPwMS to discuss their condition in a safe environment.

Participants spoke about the amount of **verified and unverified information online** which makes it “difficult for people to make correct decisions or know whether information is reliable.” **Social media sites** such as Facebook are great for YPwMS connecting with one another. However, we all experience information overload. How do YPwMS decide what is right for them? MS societies can provide direction and some stability in terms of reliability of information.

The possibility of having an interesting website with information booklets, events, regional conferences and support was discussed. It would include weekends for newly diagnosed, events for partners and family members and the opportunity to speak with other PwMS.

## Which kind of information?

Some YPwMS do not want to know negative information. However, **people do want realistic information about their options**. Also, information presented in a manner that respects the individual's situation i.e. a patronising neurologist who does not take time to discuss options or who withholds information is discouraging and damaging.

YPwMS want information about disclosure of their condition to family, friends and employers. **Their rights and/or protection in employment** (law, issues of constructive dismissal). **What about having children? How to manage relationships, issues on sexuality, services available.**

Everyday management strategies are a means of **empowerment**, enabling YPwMS to make decisions and live to the fullest of their capabilities.

**Newsletters, online forums, emailing lists** are all cheap ways for YPwMS to get reliable information. Some societies provide newsletters and magazines by post.

When YPwMS get together they can **share experiences, information on treatments and management**. Young people are generally less conservative and want to discuss problems they're having with relationships, their sex lives and other personal aspects that older people living with MS are not used to discussing. If MS Societies are not comfortable facilitating such discussions, the Society should provide facilitators who are.





## INFORMATION AND YOUNG PEOPLE WITH MS

*Ann from Poland*

When young people are diagnosed with MS, they have particular concerns and questions: *How will my life change? Will I have to adapt my activities? Can I have children? Can I continue to work? What kind of treatment is available?*

Most YPwMS use the **internet** as their primary source for accessing information about MS as it is the quickest and easiest means. The main problem with the internet, of course, is the **lack of credibility**: much of the information published online has no editors or fact-checkers. Information is only reliable when the sources are credible, such as pages created by MS Societies, government agencies, or forums in which people can share questions and answers. Even in forums, though, information must be filtered as one person's experience can differ from another's.

Many newspapers and medical journals also offer a means for YPwMS to learn about MS. These sources are highly reliable and often publish information about the **latest medical treatments**, technologies and equipment that may help address the everyday difficulties of living with MS.

Delegates at the Youth Congress unanimously agreed that a mailing list should be set up to disseminate current, relevant information. In addition to making it easier to obtain reliable information, a mailing list would also give YPwMS a chance to share with their peers on many topics – including their fears, feeling, troubles and solutions.



## YOUNG PEOPLE WITH MS AND MS SOCIETIES

*Shana from United Kingdom*

### Involvement of YPwMS

Often MS Societies/branches say, “We tried setting up an event for young people but they didn’t come. So they evidently don’t really need/want it”. However, many participants had examples of **very successful youth events**. It was felt that often MS Societies do not properly ask young people what they actually want. And MS Societies can easily ‘give up’ on young people. YPwMS often do not want to attend branches or events with older people.

Most countries do not have a **central budget for YPwMS**. Therefore it is regional branches or organisations which have responsibility for organising events and support for YPwMS. This means that provision for Young People is very variable is dependent on where they live. There is not a consistent support network throughout the country. Italy is trying to organise groups for YPwMS in each region as well as a national programme which is an excellent example of good practise.

Countries such as Denmark and Italy have ‘**Youth councils**’ as part of their **National Organisation**. This seemed to be a really good way of engaging YPwMS with the MS society and guiding the MS society about what they want.

Participants discussed the importance of not only involving and supporting YPwMS, but involving friends, families and partners in activities and information provided by the MS Society.

## YPwMS' s needs

YPwMS need their MS Societies to provide **accurate information designed specifically for young people** about: employment, sex, continence, relationships, benefits. Many participants felt their MS Societies did not fully recognise why information, guidance and support about these issues were different for younger people to older people.

YPwMS need the MS Society to provide website information specifically for Young People and the opportunity to network and get peer support through discussion forums and facebook.

YPwMS want their **own events** such as photography courses, going to pubs, gigs, restaurants etc. They want the MS Society to enable them to **make friends whilst actually doing an activity** – not just sit around together in a branch talking about MS.

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## YOUNG PEOPLE WITH MS AND MS SOCIETIES

*Emma from Ireland*

### Involvement of YPwMS

MS societies across Europe have trouble engaging with YPwMS, perhaps due to the historical ways and means of working with and for PwMS. Now, it is not only about giving information to YPwMS; MS Societies need to ensure the channel for information is open to information *flowing back to* the societies. If there is a constant exchange of ideas and information gives everyone a stake in the society, strengthening it now for the future.

Involving YPwMS in the MS Society means engaging with the YPwMS as partners rather than as clients. It is the experience of participants that MS Societies are afraid of the changes that need to take place but YPwMS are also cautious of engaging with their society. By learning from the mistakes (lack of communication, discussing and participation), new ideas, stronger connections and a positive revitalising of MS Societies will take place. YPwMS are the future of the MS societies but YPwMS must also be willing to learn from the experience of others.

In the UK and Ireland, the local branch structures create a disjointed approach. Local branch meetings can be unappealing for YPwMS (too much bureaucracy, generation gap). Some branches have events including day-trips and family outings but these are not arranged in all branches, with some YPwMS never having the opportunity to take part. This inconsistency is something national societies need to change for YPwMS outside of the active branches.

Some YPwMS don't want to be involved or participate in the Society events. They want reliable information but do not want the personal connection with the society.

## Events

*National Conferences:* A conference for YPwMS was held in The Netherlands with more than 400 participants. This September in Dublin, Ireland YPwMS will have opportunities to meet one another and create groups for young people around the country. There must be follow up by the societies and the enthusiasm of participants used to further network between people.

*Social Events:* Participants want MS Societies to provide the space and time for YPwMS to meet. A participant from Norway told of pizza nights, movie trips and local networking events that have been very successful. The Norwegian society also had a trip to the Canary Islands for 40 YPwMS, people who are still meeting and supporting one another. If the society provides the opportunities for people to get together they will engage with one another and strengthen the society. A social group run by and for YPwMS in a local coffee shop/pub is low cost and provides a safe space for people to get together and talk.





## NETWORKING FOR YOUNG PEOPLE WITH MS

*Inès from Spain*

**Social networking** is an incredibly powerful and useful tool: it is accessible, easy to use and provides a means of instantaneous communication with no geographical limits. YPwMS can profit from social networking devices to contact their peers, promote awareness of MS, and share experiences and information.

Participants in the EMSP Youth Congress unanimously agreed on the importance of finding useful and reliable sources of information, which can be difficult when faced with the sheer quantity available on the internet. Official websites, forums and networks devoted to YPwMS help direct people to trustworthy sites where information is carefully researched and edited.

**Exchanging experiences with their peers** helps YPwMS feel understood and supported by a network of people in similar situations. The potential for **anonymity** is another positive aspect of online networking, as many YPwMS would prefer not to publicly identify with their disease. It is not easy to deal with a diagnosis of MS and online networking can be useful to find relevant societies, groups, activities and people. Networks for YPwMS should take into consideration their particular needs, concerns, fears and questions. These networks should be a place where people feel comfortable **expressing their feelings and thoughts without being judged**.

When creating an **online network** for YPwMS, it is important to consider what information the users would like to have posted and what services they would like to see offered. A YPwMS would be the perfect candidate for the role of network moderator, as he/she

may be more attuned to the needs of users. Doctors, psychologists and researchers could be involved in the creation of such a network and provide regular updates on treatment options. Online networking can be used in a variety of ways:

- Promote awareness of MS around the world;
- Promote fundraising events related to MS;
- Allow YPwMS to contact and discuss with their peers, with the option of remaining anonymous
- Help friends and families of YPwMS find information relevant to them as support figures and care givers.

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## FUNDRAISING BY YOUNG PEOPLE WITH MS

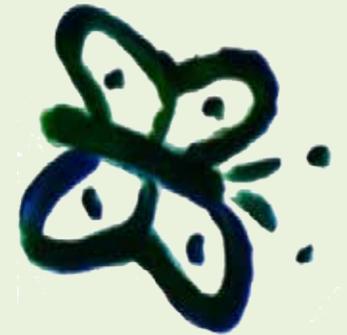
*Camille from France*

The reality of a youthful, active YPwMS contradicts the stereotypical image many people hold of PwMS as severely handicapped, whether the person still has full mobility or not. The fact that many PwMS are young and dynamic can be an excellent asset for fundraising for MS societies as it attracts attention and challenges expectations. At the second annual Youth Congress, held in conjunction with the EMSP Annual Congress (12 – 13 May 2011, Brussels), youth delegates from participating countries expressed their own potential to **facilitate and catalyse** fundraising for MS.

A round-table discussion produced many **fruitful, inventive ideas of ways to raise funds**. The delegate from the UK suggested organising a poker tournament or a concert with popular bands, and the Italian delegate had the idea to coordinate a photo exhibition. After the exhibition, the photos would be auctioned off with all funds going to the MS Society. This idea has a lot of potential: the show could be built around a particular theme, or the photos could be taken by PwMS. Several delegates suggested selling items such as apples or flowers – objects that are simple, inexpensive and cheery.

When the idea of organising a **particular Challenge** came up, everyone responded very positively. Challenging group adventures, such as mountain climbing, have already proved to be greatly successful in terms of both fundraising for MS and empowering participants. All delegates at the Youth Congress expressed the desire to explore these opportunities further, saying that the challenge should be **something “spectacular”** in which all YPwMS can be proud to participate. There is great potential for

international participation, bringing YPwMS from various European countries together with a **common goal**. Money raised from such a Challenge could fund research, as this is a cause that would eventually benefit all MS Societies.



## **FUNDRAISING BY YOUNG PEOPLE WITH MS**

*Shana from United Kingdom*

### **Funding of YPwMS Activities**

Most countries had very little specific funding for programmes for YPwMS. Participants felt that YPwMS were often disengaged with the society as their needs are not met. Participants felt that the MS Societies / branches are short-sighted about their lack of provision for Young People - the more YPwMS feel engaged the more likely they will be to get involved with fundraising for the society.

Where groups for YPwMS do exist, they can struggle to get funding from the MS Societies for their group. For example MS Societies are more likely to support specific 'activities' than to support transport costs for people to meet in a café or pub. There is a lack of understanding about what Young People need.

Participants felt that Young People's groups should be funded by national society, but young people should be involved in planning, organisation and extra fundraising.

### Fundraising by YPwMS

YPwMS often want to involve other people in their fundraising events, not just people with MS. For example running charity gigs or concerts - these are 'normal activities' which can involve everyone not just events for people with MS. Young people should decide what fundraising events will work best with their peer group

Social networking such as Facebook and Twitter can be used efficiently and cheaply to tell everyone about fundraising events.

There was a great deal of discussion about how to raise the profile of MS. Cancer, Aids & Diabetes charities have the monopoly in many countries. Need to get lots of media attention. In some countries there are big departments of the National MS Society dedicated to fundraising. In others such as Norway and Belgium the MS Society is funded by the government. So the nature of the organisation changed the way fundraising worked and the way money is distributed.

Countries with National Service can utilise volunteers for MS Society and fundraising activities.

In Italy, a major bank sponsors the yearly youth congress. Businesses can be approached for funding and sponsorship. There are also grants available - eg from lottery. Romania, Poland and Czech talked about the Education and Culture Grant. Czech Republic Young People's Group got money from government and business to make a film about MS and raise awareness.

## CONCLUSION

MS affects all participants whether as a person with the condition, working for a national society or a volunteer. The discussions were broad, enthusiastic and gave everyone a chance to hear of the experiences in other nations. Our lives are all enriched when we share ideas and create the energy for positive change in our respective countries. The energetic discussion and relationships begun in 2010 have continued in Brussels. Now the EMSP and all participants have an opportunity to work together and improve the lives for all Young People with MS.



This image has been painted by Young People with MS during the EMSP Youth Congress 2011

