

## European Youth Event 2016

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### Young Patients: Ready, Brilliant and Able to Work!

European Parliament, Strasbourg  
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## About the European Young Patients Group

The **European Young Patients Group (EYPG)** is a joint initiative between youth patient representatives of the European Patients' Forum (EPF) and the European Multiple Sclerosis Platform (EMSP). The aim of the group is to share first-hand experiences and practical advice, change perceptions and educate the wider society on young people who develop and present with chronic conditions in the workplace.

The **European Patients' Forum (EPF)** is an umbrella organisation that currently represents 67 member patient organisations from specific chronic disease areas operating at EU and national level. The EPF helps to empower patients' groups through educational seminars, policy incentives and projects with the overarching vision for all patients with chronic and/or lifelong conditions in the EU to have access to high quality, patient-centred equitable health and social care.

The **European Multiple Sclerosis Platform (EMSP)** represents the interests of 40 member societies in 35 European countries engaged in advocacy and raising awareness of multiple sclerosis (MS). The EMSP is committed to ensuring high quality equitable treatment and support for people with MS throughout Europe.

## Introduction

### EUROPEAN YOUNG PATIENTS GROUP (EYPG) REPRESENTATIVES



**Ioanna Christodoulidou**

European Multiple Sclerosis Platform (EMSP)

*Ioanna is 30 years old and was diagnosed with MS in 2003. She is a youth representative for the national society for MS in Greece and EMSP. Her background is in Sales and Marketing.*

**Mario da Luz**

European Multiple Sclerosis Platform (EMSP)

*Mario is a 27-year-old architect from Portugal. He was diagnosed with MS in 2014 and has since been volunteering as a patient advocate for the Portuguese MS society and EMSP.*



**Thomas Hough**

European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)

*Thomas is 28 years old and was diagnosed with Crohn's disease in 2011. He blogs about his condition and the adventures it motivates him to go on under the alias 'Chronic Adventurer'. He volunteers for Crohn's and Colitis UK and EFCCA.*

**Lembe Kullamaa**

Estonian Chamber of Disabled People (EPIK)

*Lembe is 20 years old and was diagnosed with Juvenile Idiopathic Arthritis (JIA) at the age of seven. She is an undergraduate at the University of Tartu in Estonia and has represented the EPIK and been a member of the EPF Youth Group since 2014.*



**Yolita Pavlova**

Confederation "Health Protection" (KZZ)

*Yolita is a 25-year-old Sociology graduate from Bulgaria and has volunteered for more than five years supporting children and families of alcoholics. She is a youth representative with the KZZ and joined the EPF Youth Group in 2012.*

**Patrik Puljić**

European Multiple Sclerosis Platform (EMSP)

*Patrik is 24 years old and is an active youth leader of his local MS association in Zadar, Croatia. He joined the EMSP Young People's Network in 2015 and is currently studying Geography at Zadar University.*



**Jacobo Santamarta**

European Multiple Sclerosis Platform (EMSP)

*Jacobo is a 30-year-old trained lawyer and been living with MS since 2007. He has been a youth representative with his local MS organisation in Spain for five years and joined the EMSP Young People's Network in 2015.*

**Polis Stavrou**

International Diabetes Federation Europe (IDF Europe)

*Polis is a 26-year-old mental health nurse from Cyprus and was diagnosed with diabetes at the age of six. He is a youth member of the Cyprus Diabetic Association and IDF Europe as well as a board member of the EPF Youth Group.*



**Laurence Woollard**

European Haemophilia Consortium (EHC)

*Laurence is a 26-year-old severe Haemophiliac from the UK. He is a Youth Ambassador with the national Haemophilia Society and the EHC. Currently, he is completing a 3-month traineeship with the EPF in Brussels.*

**Anna Zaghi**

European Multiple Sclerosis Platform (EMSP)

*Anna Zaghi is 26 years old and was diagnosed with MS in 2012. She is currently involved in fundraising activities for the Italian MS Society. She is a member of the EMSP Young People's Network and joined the EPF Youth Group at the end of 2015.*



## SUPPORTING STAFF

<b>Danielle Flores</b>	Junior Project Officer – European Patients’ Forum (EPF)
<b>Elisabeth Kasilingam</b>	Programme Manager – European Multiple Sclerosis Platform (EMSP)
<b>Emma Rogan</b>	Project Coordinator – European Multiple Sclerosis Platform (EMSP)
<b>Laurène Souchet</b>	Policy Advisor – European Patients’ Forum (EPF)
<b>Valentina Strammiello</b>	Programme Officer – European Patients’ Forum (EPF)

## GENERAL OBJECTIVES AND STRUCTURE OF THE WORKSHOP

The workshop<sup>1</sup> was organised in the framework of the European Youth Event (EYE) 2016 and corresponded with one of the five main programme themes titled, *Exclusion or Access: Crackdown on Youth Unemployment*.

The physical and emotional symptoms of chronic conditions, together with social stigma and attitude, create significant barriers to young patients in the job market. With appropriate support, they, like all enthusiastic young people, can be assets for employers. Through interactive discussion, creative expression, education and open dialogue, the workshop aimed to:

- Challenge expectations and inaccurate perceptions about the abilities of young people with chronic conditions
- Tackle societal beliefs and stereotypes of individuals with chronic conditions
- Stimulate discussion to explore concrete solutions and develop practical actions for young people and their allies accessing employment
- Steer change to ensure young patients benefit from equal opportunities and treatment at work.

By addressing these specific objectives, the workshop was to ultimately raise awareness of the extra burdens faced by young people with chronic conditions transitioning from education to employment, as well as bringing public attention to the stigma and discrimination that exists at both the recruitment stage and in relation to employees disclosing their health conditions. It also was to compliment and strengthen the EPF and EMSP’s wider initiatives on tackling the multiple forms of discrimination faced by patients with chronic conditions.



<sup>1</sup> For the full workshop agenda, please refer to Annex I on page 11.

A month preceding EYE, the EYPG used social media to promote and increase awareness of the workshop and its broader topic, at one point reaching close to 1000 users on Facebook. On the day of the workshop, participants were encouraged to engage and exchange ideas on Twitter using the hashtags #EYE2016 and #Fit2Work, where key notes and points of discussion were being captured<sup>2</sup>.

## Opening remarks: Why is employment such a big deal?

The workshop facilitators, Anna Zaghi and Laurence Woollard, opened proceedings by highlighting the importance of employment and the fact it brings lifestyle options, new opportunities, structure, social and personal fulfilment, plus financial independence. For some young people, navigating the pathway to employment is increasingly challenging but this is exacerbated when you have a chronic condition. They made reference to a research study by The Work Foundation<sup>3</sup>, which suggests young people with chronic conditions have an increased probability of being unemployed, earning less and attaining fewer, and lower, qualifications than their healthy peers.



## Plenary session: *The Youth Factor*

To demonstrate how a young person can be discriminated against in accessing the labour market on grounds of their pre-existing chronic condition and/or disability, Patrik Puljić, Ioanna Christodoulidou and Polis Stavrou of the EYPG performed a short role play depicting a job interview<sup>4</sup>. Due to her chronic condition, the young candidate expressed her reservations about travelling abroad for work, which caused the interviewers to react negatively and eventually decide that she was too much of a liability and cost to the company.

**“I was worried about declaring my disability before my interview due to the negative impact other people have told me about.”**

**Simon  
(Workshop participant)**

Simon, a young EYE participant, opened the debate by sharing his own experiences as a wheelchair user. Having been rejected on more than one occasion without valid reason, Simon is concerned that his disability has an immediate negative impact on interviewers, given that he does not disclose it on the application. This gives rise to the opinion that Simon secures an interview because of his credentials but is considered to be less able to work upon meeting employers in person. Also, Simon felt that by disclosing his condition he would be invited to interviews just to let the company satisfy its diversity quota.

<sup>2</sup> For a selection of the top Tweets, please refer to Annex III on page 16.

<sup>3</sup> [The Work Foundation: Don't stop me now: supporting young people with chronic conditions from education to employment](#)

<sup>4</sup> For the full role play script, please refer to Annex II on page 11.

EYPG representative Lembe Kullamaa raised the fact that young patients are limited by career choices. She explained that her joint condition prevents her from pursuing occupations which involve physical labour. This was acknowledged by others in the room and that a more transparent recruitment process is required.

## Interactive session A: Raising awareness amongst employers

The next session focused on the perspective of employers. Anna began by discussing about EMSP's *Believe and Achieve*<sup>5</sup> internship programme, which aims to provide young people with MS the opportunity to access meaningful, paid employment with important businesses.



As an alumna of the programme, she spoke positively about her experience and emphasised that *Believe and Achieve* is beneficial for both parties. It gives patients the opportunity to demonstrate their skills and abilities but also brings internal transformation to a company and greater understanding of supporting employees with chronic conditions through minimal accommodations (e.g. work station close to the toilets, dedicated quiet zone for short breaks). The

outcome of the project includes a *Practical Toolkit*<sup>6</sup> with such guidelines and good practices. Since the programme's inception in January 2015, 15 young people with MS secured internships, which have led, in most cases, to further employment.

There was an open exchange of opinions as to why employers would not hire young people with chronic conditions. Ioanna highlighted the financial implications, such as the perceived cost of making adjustments and expenses related to potentially higher levels of absenteeism. Lembe added that employers fear the young patient would not perform as well as his/her colleagues and this social stigma and discrimination needs addressing. Other examples were the possible need for extra supervision and lack of awareness of how to manage chronic conditions in the workplace.

**"Employers need to be educated in how to make small adjustments to support skilled people into work."**

**Lembe  
(EYPG representative)**

The participants then considered how they can collectively influence the attitude of employers. Key ideas included equality and open-mindedness, creating a workforce that reflects the diverse customer it serves, providing staff training, plus financial incentives like tax breaks or subsidy schemes to help with changes/improvements to the workplace. Lembe shared that her national government in Estonia

<sup>5</sup> For more information on *Believe and Achieve*, please visit <http://www.emsp.org/projects/believe-and-achieve/>

<sup>6</sup> <http://www.emsp.org/wp-content/uploads/2016/01/PPP-Working-Out-MS-in-the-Workplace-Toolkit-Jan2016.pdf>



allocates extra funds for employers to adjust the working space and make it accessible. Nevertheless, this is not the case across the EU and without having provisions for young patients to gain credible work experience, this will have a long-term impact on their employment prospects.

## Interactive session B: Cultural shift & challenging expectations

The final session showcased how mental strength is key to young patients combating stigma and discrimination and how they can transform a negative life experience into a positive future.

EYPG representative Jacobo Santamarta shared his insight as an employee for a petroleum company in Spain. Having applied for a role over four years ago, Jacobo reported that probably his employer hired him on the basis of his MS because the Spanish government introduced incentives for the recruitment of people with chronic conditions and/or disabilities, such as a reduction in the employer's social security contributions.

Having been in the job for six months and without any major health symptoms, the company downgraded Jacobo to a more administrative position that required no special background or skills. This sense of isolation really affected his confidence and it was discouraging that the company considered him incapable of doing his work. Although Jacobo's physical state has changed since then, his mental capacity to do the job remains the same.



Jacobo's experience shows us the consequences of ignorance and public misperception about young people with chronic conditions. It was agreed that we should challenge existing assumptions and thinking to ensure employers are maximising new ways of working with young patients.

Laurence summarised by explaining that securing a dream job can be highly challenging for young people with chronic conditions. However, overcoming obstacles can make you a stronger business leader and bad experiences should not hold you back; they simply give you more room to grow.

## Conclusions and Recommendations

The workshop demonstrates how many issues surrounding young people with chronic conditions transitioning into the labour market are still prevalent. The expectation of discrimination and stigma in the workplace, along with the unwillingness to disclose their condition when applying for a job for fear of rejection are confounded by young patients' experiences of negative employer attitudes.

Moreover, the concept of quota systems and giving people with chronic conditions and/or disabilities preference among applicants for certain jobs possibly suggests that they are employed *because* they have a chronic condition and/or disability, not because of their abilities. This unambiguous form of positive discrimination also affects how young people manage information about their health. They feel forced to share about their condition in order to get an interview, however by doing so they risk being subjected to negative reactions in the interview or at the workplace.

Young people with chronic conditions have a great deal to contribute to the workplace and more action should be taken to encourage and support employers with hiring them. Training and resources should be provided to managers and employees to raise awareness of the impact that chronic conditions can have on an individual, and how they can be assisted through small adjustments or specific care requirements. Employees should not assume what someone can or cannot do and how their condition affects them, therefore a place for an open discussion should be created. In addition, where quota systems apply, they should be re-evaluated and designed so as to recruit young patients on merit, in competition with other workers without a chronic condition and/or disability.

We would like to encourage all employers and employees to use the existing tools, such as the *Practical Toolkit for Employers*, to initiate dialogue and action plans to offer equal opportunities and healthier workplaces for everyone.

## List of Annexes

### ANNEX I: THE AGENDA

#### Introduction

- 15:00- 15:05** *Welcome and vision of the workshop* - Emma Rogan, EMSP Project Coordinator
- 15:05- 15:10** *Expected outcomes of the workshop* – Laurence Woollard, EPF Youth Trainee

#### Plenary Session: The Youth Factor

- 15:10- 15:20** *The Job Interview* – Roleplay by EPF and EMSP Youth Group members
- 15:20- 15:40** Participant discussion – *What qualities do young people with chronic conditions bring to an employer? What challenges do they face when finding a job? How can these barriers be overcome?*

#### Interactive Session A: Raising awareness amongst employers

- 15:40- 15:50** *How do employers deal with illness in the workplace?* – Emma Rogan, EMSP Project Coordinator  
Case study: *Believe and Achieve* campaign by EMSP
- 15:50- 16:00** *How can you influence the attitudes of employers?* – Laurence Woollard, EPF Youth Trainee

#### Interactive Session B: Cultural shift and challenging expectations

- 16:00- 16:10** *The relationship between mental health and employment* – Elisabeth Kasilingam, EMSP Programme Manager
- 16:10- 16:20** Participant discussion – *Who is your role model? What image best defines work for you?*

#### Closing Remarks

- 16:20- 16:30** *Feedback and recommendations for future activity* – Elisabeth Kasilingam, EMSP Programme Manager

## ANNEX II: ROLE PLAY

### The Actors

- **Gareth**, Human Resources Manager of the record label
- **Maria**, Artist Relations Manager who will line manage the successful candidate
- **Rebecca**, a young motivated application with a chronic condition

### Part I: Pre-interview

*(Gareth and Maria are sat discussing Rebecca's application)*

**Gareth:** I really like the look of Rebecca's application. She clearly has a passion for this industry and it would be an ideal starting position for her.

**Maria:** I agree! Her application really stood out from the rest and she seems exactly what I need in the team.

**Gareth:** I have a good feeling about this... If Rebecca comes across as well as she does on paper, then I will have no hesitations in hiring her.

**Maria:** Great, let's invite her in...

### Part II: The interview

*(Rebecca, the interviewee, enters the room)*

**Gareth:** *(Rises to greet Rebecca and offers his hand)* Hello, is it Rebecca? I'm Gareth, the HR manager here at the label.

**Maria:** *(Also rises to greet Rebecca and offers her hand)* Welcome Rebecca. My name's Maria, I'm the Artist Relations Manager and will be line managing the successful candidate.

**Rebecca:** *(Shakes interviewers' hands respectively)* Hello, thank you for taking the time to see me today.

*(Everyone sits)*

**Gareth:** So, Rebecca, why don't you start by telling us a little bit about yourself?

**Rebecca:** *(Speaking clearly and confidently while making good eye contact)* I've recently graduated with a Masters in Music Business from Manchester University, where I was also President of the Music Society. I've been running a successful gig night in the city for the past two years, which is now

attracting lots of industry buzz and attention. I now want to take my first step into the record business through your internship scheme with the goal being to secure a full time position.

**Maria:** Sounds great! So why are you interested in working for our company?

**Rebecca:** The label's reputation and awards speak for itself! I would be proud to work for a company with such a long history of chart success and development of new artists. I'm also aware that the label's culture supports learning and development on the job, which is really important to me at this early stage of my professional career.

**Gareth:** You've done your research... What's your expectations of the role?

**Rebecca:** Ultimately, I want to be in an environment where I can contribute, learn and develop as a person and professional, as well as have broader exposure to the label and its artist roster. It is an opportunity to have quality, hands on experience in a field that I am passionate about and understand the different elements that go into releasing a record.

**Maria:** At this point, I should mention that the role will require you to travel abroad, mostly outside of Europe, for several days and weeks at a time to meet and work with our artists and clients. This can sometimes be announced at the last minute – is this OK for you?

**Rebecca:** *(Pausing for thought, then answering in a hesitant manner)* Well... I think so...

**Maria:** *(Looking bemused)* You think so?

**Rebecca:** *(Following a deep breath)* Thing is, I have this particular medical condition whereby I need to take regular medication. On bad days, it can sometimes lead to hospitalisation...

*(Gareth and Maria look puzzled if somewhat discouraged at hearing this news)*

**Gareth:** What does this exactly mean, Rebecca?

**Rebecca:** I appreciate your artists travel to all corners of the world, so I would just need to make sure there is appropriate medical support and treatment supply wherever I'm staying. I'm also wondering, does the company have a private health insurance plan to cover any medical expenses? This would make me feel a lot more comfortable going abroad.

**Maria:** *(In an unsupportive tone)* Erm... We would have to check... Not all interns are offered healthcare coverage...

**Rebecca:** *(Feeling slightly dejected and looking into lap)* Oh... OK...

**Gareth:** *(In an inquisitive manner)* So, are you suggesting you would be absent from work quite regularly?

**Rebecca:** *(Hesitating again)* No... well, it's hard to say... My condition can be very unpredictable and I may fall unwell all of a sudden. But my medication is some of the best and I have very good health consultants who support me with managing difficult episodes.

**Gareth:** Right, right... It's a tricky one... I mean, that's not to say you couldn't do the job...

*(In an effort to downplay his negative reaction to the news of Rebecca's health, Gareth starts looking through her CV)*

My only issue is regarding your experience; as one of the top labels in the country, we attract the best talent with proven experience in the field and normally require at least 12-months experience for our internships.

**Maria:** *(Following her colleague's lead)* Gareth's right, it's a very challenging workplace, so we need to feel confident the successful candidate is up to the task and can fit naturally within the team.

**Rebecca:** *(Having sensed the interviewers are off put by the news of her health, Rebecca tries reassuring them)* I want to assure you that I have the ability and work-ethic to be a success at this company. What I may lack in experience I make up for with my enthusiasm and commitment. And in the event my condition prevents me from working or travelling, I will go above and beyond to make up for lost time and do whatever it takes to meet deadlines.

**Gareth:** *(Rises to say goodbye and offers his hand)* We're going to leave it there, Rebecca. Thanks for coming in, it's been a pleasure to meet you.

**Maria:** *(Also rises to say goodbye)* Thanks Rebecca, we'll be in touch over the next week.

**Rebecca:** Thank you for the opportunity.

*(Rebecca exits to the room)*

### Part III: The debrief

*(Gareth and Maria are sat reflecting on Rebecca's interview)*

**Gareth:** I had high hopes for Rebecca but she's too risky for the company. With a longstanding health problem, who knows when she'll be off work?!

**Maria:** I understand Gareth but she presented herself really well. I think she would be a really valuable asset to the team and I would consider giving her a chance...

**Gareth:** Our artists and clients are too demanding. We have a reputation to uphold and require a degree of reliability and flexibility from our staff to exceed their expectations. The uncertainty surrounding Rebecca's illness is too great in my opinion.

**Maria:** I'm worried she may have noticed our negative reaction to the news of her condition. This could come back at us if we're not careful, especially if we decide not to hire her...

**Gareth:** I'm telling you, my Director does not like liabilities. Rebecca would bring extra costs to the company and we need someone who can handle the workload.

**Maria:** It's really unfortunate but I know you're right. On this occasion, we'll have to go with another candidate.

**END.**

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## ANNEX III: BEST OF TWITTER CHAT #FIT2WORK

**@TheWoollard:**

*Employers need to see the skills and abilities first and not allow someone's health to cloud their judgement. #Fit2Work #EYE2016*

2:17 PM – 20 May 2016

**@EPFyouth:**

*Believe and Achieve by @eumsplatform has really helped me to show my skills to businesses and support employers – Anna. #Fit2Work #EYE2016*

2:36 PM – 20 May 2016

**@eumsplatform:**

*@EPFyouth we are always there to support young ppl w/ #MS like Anna. Together we can #WorkOutMS! #Fit2Work #EYE2016*

2:40 PM – 20 May 2016

**@EPFyouth:**

*Employees sometimes assume what you can do before actually asking you, why don't they just ask? – Jacobo @eumsplatform #Fit2Work #EYE2016*

2:56 PM – 20 May 2016

**@EPFyouth:**

*Education of general public is key, just because we are not Paralympians doesn't mean we can't be a great success at work – Simon #Fit2Work*

2:59 PM – 20 May 2016

**@EPFyouth:**

*Employer was shocked I didn't tell them I had MS but gave me great support and things were so much better – Patrik @eumsplatform*

3:06 PM – 20 May 2016

**@ForEveryIBD:**

*When going for interviews I was worried about sharing my illness but I have never regretted it - #Fit2Work @eupatientsforum*

3:14 PM – 20 May 2016

**@EPFyouth:**

*There is so much fear to share your illness with friends, strangers and employees due to stigma – Anonymous #Fit2Work #EYE2016*

3:16 PM – 20 May 2016



## ANNEX IV: FURTHER READING

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- European Patients' Forum (EPF) - [Equal Treatment for Patients in Education and Employment](#) (2016)
- The European Network For Workplace Health Promotion (ENWHP) – [Promoting Healthy Work for Workers with Chronic Illness: A Guide to Good Practice](#) (2012)
- Antonio Corral, Jessica Durán and Iñigo Isusi, IKEI Research and Consulting - [Employment Opportunities for People with Chronic Diseases](#) (European Foundation for the Improvement of Living and Working Conditions, 2014)
- Eurofound - [Active Inclusion of Young People with Disabilities or Health Problems](#) (Luxembourg: Publications Office of the European Union, 2012)