A Need for Visibility in Support Systems

Second High Level Event at United Nations for NGO Committee on Rare Diseases

Lieven Bauwens
Secretary General, International Federation for Spina Bifida and Hydrocephalus

Board member, Eurordis

21 February 2019
Leave No One Behind!
Nothing About Us, Without us!

CRPD and Optional Protocol Signatures and Ratifications

- Not Signed
- Signed Convention
- Signed Convention & Protocol
- Ratified Convention
- Ratified Convention & Protocol

As of 19 September 2007

Invisible?
Article 18 - Liberty of movement and nationality

1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including ...

2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.
Example from Ethiopia

RESEARCH ARTICLE
High burden of neural tube defects in Tigray, Northern Ethiopia: Hospital-based study

Birhane Alem Berihu1,*, Abadi Leul Welderuafael1, Yibrah Berhe1, Tony Magana2, Afework Mulugeta3, Selemawit Asfaw3, kibrom Gebreselasie1

1 Department of Anatomy, Institute of Biomedical Sciences, College of Health Sciences, Mekelle University, Mekelle, Ethiopia, 2 Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Mekelle University, Mekelle, Ethiopia, 3 Department of Obstetrics and Gynecology, School of Medicine, College of Health Sciences, Mekelle University, Mekelle, Ethiopia

Received 5 February 2018; received in revised form 11 June 2018; accepted 14 July 2018

Abstract

Maternal risk factors associated with neural tube defects in Tigray regional state of Ethiopia

Birhane Alem Berihu1,*, Abadi Leul Welderuafael1, Yibrah Berhe3, Tony Magana1, Afework Mulugeta3, Selemawit Asfaw3, Kibrom Gebreselasie1

1 Department of Anatomy, Institute of Biomedical Sciences, College of Health Sciences, Mekelle University, Mekelle, Ethiopia, 2 Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Mekelle University, Mekelle, Ethiopia

Received 4 April 2018; received in revised form 3 December 2018; accepted 26 December 2018

Nutritional status among women whose pregnancy outcome was afflicted with neural tube defects in Tigray region of Ethiopia

Abadi Leul Welderuafael1, Birhane Alem Berihu1,*, Yibrah Berhe3, Tony Magana1, Selemawit Asfaw3, Kibrom Gebreselasie1, Ezra Belay3, Hayelom Kebede1

1 Department of Pediatrics and child health, School of Medicine, College of Health Sciences, Mekelle University, Mekelle, Ethiopia, 2 Department of Anatomy, Institute of Biomedical Sciences, College of Health Sciences, Mekelle University, Mekelle, Ethiopia
Perception
Rare diseases are complex and often invisible

Symptoms vary & can be invisible in many ways...

"One day you appear completely healthy, the next day you are sick, and two days later you appear completely normal again" Female, Spain

I don't look ill but am very ill with a condition which no one understands or has heard of” Female, United Kingdom

...underreporting, unknown diagnosis or stigma.

Illustrative photo. This presentation does not necessarily reflect the position of the person in this photo. Source: EURORDIS Photo Contest
People living with a rare disease have serious difficulties with several Activities of Daily Living

More than 7 in 10 have difficulties with
- Daily activities & tasks
- Understanding & learning
- Motor/sensorial functioning

More than 5 in 10 have difficulties with
- Taking care of finances & everyday administrative tasks
- Communicating with others
- Controlling behaviour

More than 4 in 10 have difficulties with
- Personal care activities

8 in 10 face difficulties in more than one aspect of everyday life

Care pathway is complex and hard to manage

Image on care pathway used for illustration purposes.
Source: Nationella Funktionen Sällsynta Diagnoser, Sweden

Survey performed via EURORDIS survey initiative Rare Barometer Voices
The appointments should be multidisciplinary allowing for the various specialists to see the person on the same day and the same place.

Besides facilitating communication and the definition of adequate treatment it would also avoid that the person has to travel to different appointments and places, being absent from work (losing income and facing discrimination at the workplace) and spending a lot in travel.”

Female, Portugal
Significant impact on professional life

7 in 10

People living with a rare disease & family carers had to reduce or stop professional activity due to the disease

The rare disease led to an income decrease for 69%

58% absent from work over 15 days/year
41% asked for special leave from work but could not obtain it

Survey performed via EURORDIS survey initiative Rare Barometer Voices
Deteriorated mental health

3 times more people living with a rare disease and carers report being unhappy and depressed than the general population*

* Rare Barometer Voices sample compared to International Social Survey Programme, 2011

Survey performed via EURORDIS survey initiative Rare Barometer Voices
A burden that heavily falls on women

The role of the primary carer for people living with a rare disease is primarily assumed by women

Who organises and coordinates care in your household?

- Mother (64%)
- Spouse (25%)
- Father (6%)
- Others (5%)
Concluding: leaving no one behind
Thank you!

Lieven Bauwens
lieven.bauwens@ifglobal.org