Factors affecting access

- Lack of disease awareness
- Barriers to diagnostics
- Access to the right HCPs / therapies
- Availability of clinical trials
- Adherence
- Stigma
- Family / carer support
- Disease-centred vs patient-centred care
Lack of Disease Awareness

- Lack of awareness about disease states
- Lack of awareness about prevalence & signs
- Symptoms go unrecognized or misinterpreted
Barriers to Diagnostics

- Imaging and advanced diagnostic capabilities
- Value of proper diagnosis
Access to the right HCP/s

- Medical specialists
- Speech therapists
- Occupational therapists
- Behavioral health practitioners
Therapeutic Access

Delays in patient access following market authorisation

The average length of time from market authorisation to the completion of post-authorisation processes has increased from 233 days between 2007 and 2009, to 318 days between 2014 and 2016.
Europe comes up short on drug supplies

France has joined the Netherlands in pushing for an EU-wide approach to stopping drug shortages.
Clinical Trials Access

- Trials information availability
- Health literacy
- Geographical barriers
- Scheduling challenges & time constraints
Adherence

- Intentional vs. Unintentional
- Lack of information
- Out-of-pocket costs & reimbursement issues
- Side effects
- Complexity of medicine regimen

Source: The New York Times
Stigma

Living with Essential tremor

Living with Tardive dyskinesia

Living with Tourette syndrome
• Medical appointments
• Medication adherence
• Symptoms monitoring
• Day-to-day support at home
Disease-Centered Care
Disease-Centered Care

- Emphasis on making diagnosis and then grouping patients by disease
- One-size-fits-all care based on disease state
- Easier for payers to rein in their budgets by using clinical pathways, step therapy and non-medical switching to minimise individualised care
Patient-Centered Care
Patient-Centered Care: the components

- Strong clinician-patient relationship
- Empowered patients engaged in shared decision making
- Policies that support therapeutic access

Leading to:

- Patients avoiding the 'one-size-fits-all/least costly' alternative health care model
- Long-term value of getting it right sooner rather than later
Patient-Centered Care: why it matters

• The average person living with a Long Term Condition in Europe spends approx. 4 hours per annum with a clinician.

• The other 7,650 hours we are on our own

Let’s ensure this tiny but precious time delivers what patients need to live their lives well
Patient-Centered Care: Communication

• Knowing – or imparting – what treatments / support are available, safe and efficacious sounds easy

• We know from what we are hearing here today that it is not

“The problem with communication is the illusion that it has occurred”  G. B. Shaw
Conclusion

So let’s commit to addressing these access issues which are unnecessarily disabling and killing millions of European citizens.

It is surely a dereliction of duty not to do so?
Thank you for your attention