

GROUP D : Access to treatment discussion report

- Building blocks need to be in place
 - Physician Training
 - Logistics
 - Facilities
 - Data – registries , clinical trial preparedness
 - Supply

- Patient journey in the bureaucracy
 - Find the right person
 - Different sense of urgency (time running out)
 - Different expectations of treatment
 - Right to health – court cases
 - Tiring – very demanding
 - Competing priorities for administration
 - Know your numbers

- Price versus Costs

- Is price the only elephant in the room ?
- Not all diseases require treatment or are amendable to treatment
- Not all drugs are expensive
- Revenue create the market
- If no market there won't be “cheaper” drugs afterwards
- Budget impact remains limited
- Lateral thinking / negotiation

- Shortage and supply
 - Shelf life
 - Size of orders
 - Price to bring the drug to market is high and small markets are not a priority.

- Framework
 - Orphan drug act / policy
 - Something you can talk about and refer to
 - Integrate cultural perspective
 - Can be a starting point
 - Acknowledge the need
 - Political willingness

Small next steps

- Collaboration – support each other - patients organisation are the driving force
- A dedicated contact person within the administration
- Know your numbers
- Use new technology (eg consultations on V-See)
- ICORD – repository of the original legislative text (links)
- Building capacity – create the conditions for access (see session)