Rare Diseases Denmark

What can patients expect from European Reference Networks? Why is it important for patients to be involved?

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Board Member EURORDIS

Or:

What´s in it for me -

as patient/family with a rare disease?

European Reference Networks for rare diseases (ERN)

- ” A framework for healthcare pathways for RD-patients through a high level of integrated expertise ………. stepvise approach”

- ” CE collaborate with patient organisations to bring in the patient perspective”

(Addendum to EUCERD Recommandations on Rare Diseases European Reference Networks)

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European
Reference Networks

My son Michael and people with Osteogenesis Imperfecta(OI) as a case-story

- *Yesterday (before google)*
- *Today (with google)*
- *Tomorrow (beyond google)*

The Goal:

RD Patients
Healthcare Pathways
through integrated expertise

Patients Healthcare Pathways

Yesterday:

- A small number of specialists in different locations
- Information through the patientorganisation(DFOI) and ”rumours”
- Referrals hard to get
- The specialist´s networks (US.)
- The role of the patientorganisations (DFOI, OI Norden, OIFE): facilitating and funding seminars, conferences, networks, individual specialists, consultations for patients (Denmark, Germany, Italy.)

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Patients Healthcare Pathways Today:

- National Centres of expertise and Healthcare Pathways for patients established – still work to be done
- National Strategy for Rare Diseases and revision of the general national plan for highly specialised healthcare and pathways
- The role of patientorganisations still important
- National procedure for CoE and ERN not established yet.

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Patients Healthcare Pathways Tomorrow:

- National centres have become part of ERNs
- Centres or experts from DK in every ERN
- Patients will benefit from the best expertise through national centres and specialists connected to ERN
- Cross-border(physically)in exeptional cases through the National Board of Health
- The role of patientsorganisations as facilitators still very important

Healthcare pathsways for RD patients- integrated expertise

- Conclusion:
  - ✓ From coincidens and luck to structure and order
  - ✓ From benefit for the strong to benefit for everyone
  - ✓ A boost for the level of expertise and development in Europa
  - ✓ Reducing inequality in healthcare for rare disease patients in Europe
  - ✓ ERNs regarded as options, not threats.

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RD Patients Healthcare pathways through integrated expertise

To Do list

1. Get hold of the person(s) / authorities representing your country in the proces around CoE and ERN and how to get ready
2. Bring up the question in every fora/committee you have
3. Get hold of your centres, experts, specialists to discuss the options and how to get ready
4. Discuss with relevant people how to prepare for the coming call
5. Liase with your contacts in your european associatiens on strategies to encourage your experts to take action

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Thank you for your attention

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