



EQUITABLE ACCESS TO RARE DISEASES & TREATMENT IN REMOTE AREAS

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PROBLEMS IN THE REGIONAL HEALTH SYSTEM (RHS) IN REMOTE AREAS

- Patients with rare diseases have to tackle a lot of problems in the Regional Health System (RHS), especially in remote areas
- At every level of the RHS. In particular:
 - Long distances
 - Lack of highly specialized Medical Staff
 - Lack of highly specialized Medical Centers

PROBLEMS ON ACCESS TO ALL SERVICES

- Diagnosis: often, misdiagnosis
- In treatment: not applied properly
- Follow-up course: often, with gaps/hiatuses

“Big-city-visit” a necessity ...

The “big-city-visit” necessity
for diagnosis, treatment and
follow-up leads to another set
of issues:

- Cost of prolonged staying (away from home)
- Absence from occupation
- Spotting the appropriate Doctor / Medical Provider
- Elevated costs in imaging exams, lab-tests
- Costs not covered / partially covered by the Social Insurance Service

After facing distance and costs issues, new problems arise:

- Search for the best appropriate Doctor (MD) /Medical Provider (MP) back home
- In the lack of expert MDs/MPs: a “compromise” with the best available ones
- The patients “teach” their condition to the health taker (and not vice-versa)
- A vicious circle: problematic treatment and follow-up (even with an established diagnosis)

HANDLING THE ISSUES IN REMOTE AREAS REQUIRES



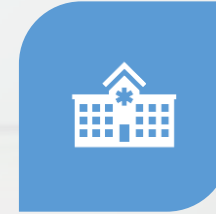
- COOPERATION OF THE
STATE AND THE RELEVANT
PATIENTS ASSOCIATION
(PA)



- FINANCIAL SUPPORT BY
THE STATE TO THE PAS



- CLOSE / CONSTANT
SUPPORT TO THE PATIENTS
THROUGH THE PAS



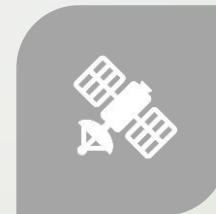
- ONGOING TRAINING FOR
MDS/MPS IN THE RARE
DISEASES FIELD



- REMOTE FACILITIES –
WHEN A CLUSTER EMERGES



- MORE FOCUSED MEDICAL
TRAINING IN THE RARE
DISEASES, ESPECIALLY ON



THE GENERAL
PRACTITIONERS (GPS) –
PRIMARY CARE LEVEL
(LONG-TERM AIM)

CONCLUSIONS

- We are “rare” but not “invisible” patients!
- We have **the same rights** as any other patient wherever they live!
- It is our right to deal with our “rare disease” and move on to our life
- It is our dedicated goal and aim!



THANK YOU FOR YOUR ATTENTION!

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