

# Premium Costumer Survey

## The Challenge

PLWRD are often dependent on social support in order to manage everyday life with a rare diagnosis or disability. A high degree of complexity in the rare pathological picture and a lack of knowledge calls for a coordinated and highly specialised effort in order to meet the needs.

## The study

With the assistance of The Danish National Centre for Social Research, Rare Diseases Denmark has conducted a quantitative survey amongst PLWRD in Denmark - "Premium Costumer" in the social system. Data was collected in 2014, results published in 2015.

- The questionnaire contains 50 questions
- 1.444 responded – 871 adult patients/ their guardian, 573 children/parents
- The respondents represent 44 of Rare Diseases Denmark's 52 member organisations plus the Network for patients and relatives affected by Ultra Rare Diseases (NURD).



## Rare Diseases Denmark

- Rare Diseases Denmark is a national alliance of 52 small rare disease societies. The societies are mainly run through voluntary work by patients and their relatives. Rare Diseases Denmark also hosts NURD – Network for patients and relatives affected by Ultra Rare Diseases.
- The work of Rare Diseases Denmark is based on volunteers and a minor professional secretariat.
- Rare Diseases Denmark has an ambition to work for all rare citizens, also those without a patient network or society.
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## Main results

### Characteristics of PLWRD

The study shows, that 7 out of 10 rare patients suffers from severe, moderate or mild loss of functional ability, while 3 out of 10 do not. More than half need special consideration in their social sphere. For families with rare children, it is as many as 3 out of 4. The impact of a rare diagnosis on the whole family is substantial, see table 1.

Table 1. The impact on the family as severe or very severe, pct. (More than one answer possible)

	Children	Adults
Economical: Our family finances has deteriorated	17 %	24 %
Practical issues: Everybody needs to do an extra effort	59 %	40 %
Emotionally: The family is deeply affected	66 %	43 %
Socially: The possibilities for social intercourse is negatively effected	38 %	40 %

### Consequences of the diagnosis being rare

Some challenges are directly linked to the diagnosis being rare:

- More than half of PLWRD experience, that being rare is a "problem enforcer" when navigating the health care sector and the social system
- More than 1 out of 5 with severe loss of functional ability meet negative reactions from their healthcare professionals
- More than 3 out of 4 points out the need of contact to other PLWRDs as the most important thing, when diagnosed – see table 2.

Table 2. What was needed the most, when the rare diagnosis was established. Pct. (more than one answer possible)

	Children	Adults
Needed psychological help or crises counselling the most	34 %	17 %
Needed social counselling the most	53 %	37 %
Needed contact to other PLWRDs the most	75 %	78 %

### Information and counseling

PLWRD experience, that their needs for information are not met. When it comes to counselling, the small, voluntary based patient organisations play an important role:

- More than 1 out of 3 is strongly unsatisfied with general information on social rights
- 9 out of 10 suffering severe loss of functional ability have to find all adequate information themselves. The dissatisfaction with information is massive for all groups
- The most used counselling is the services offered from the diagnosis specific voluntary based patient organisations. More than 60 pct. of the sum of counselling is delivered by the patient organisations.

### Social support from the public sector

8 out of 10 families with rare children and 2 out of 3 rare adults need some kind of social support. And the contact with the public system is intense. The 10 pct. of PLWRD who has the most contact with the public social system, had up to 40 different contacts in 2014 and dealt with up to 30 different professionals. However,

- more than half of PLWRD suffering from a degree of loss of functional ability experience, that their needs are unmet
- 3 out of 4 grown PLWRD with severe loss of functional ability is not satisfied with the coordination of efforts carried out by the public sector.

### Being Ultra Rare

Rare Diseases Denmark hosts a Network for patients and relatives affected by Ultra Rare Diseases (NURD) The survey shows, that members of the NURD faces even bigger challenges than other rare people:

- The members of the NURD need even more consideration in their social sphere than other rare people
- They need more help from psychologists and crises therapists when the diagnosis is established
- They are even more unsatisfied than other rare people with the information, they receive.

## Concluding remarks

The title "Premium Costumer survey" refers to the fact, that in other sectors, being premium costumer opens doors to privileges and VIP treatment. The survey shows that this is certainly not the case for PLWRD in regard to the social sector. Compared to a similar survey conducted in 2005, there have only been few improvements and the discontent with the social system has grown.

