**Connecting Rare Patients**

I want to bring up the topic *connecting rare patients* again and am looking for allianzes.

Triggered by a breakout session along our national rare disease day activities this year concerning rare disease patients without (national) patient organization I got instructed to evaluate the situation and demand in my networks – also within ERNs.

**Rationale**

There are many reasons to bring together patients with rare diseases. But while it is easy for anyone to find other sufferers in the field of common diseases, it might be very difficult in the field of very rare patients to find others - especially for naive, newly diagnosed patients, not aware of rare disease communities.

Gradually, the demand and the benefit of a connection with other patients increases with the rareness of a disease.

Benefits of connected patients have been recognized long time ago. In the German speaking language domain it got also into the standard literature of “patient friendly care”, where the connection of patients is usually on the second position of most relevant properties of patient friendly care.

There are ongoing statements for such a demand from lecturers of patient events and congresses , even for common rare diseases, like from the Sarcoidosis UK Patient Day or the PF Summit last weekend.

And there are also national activities to offer patients to connect on a systematic basis – in Switzerland. The second core benefit of the upcoming national rare disease (meta) register presented at the rare disease day in Switzerland, was the ability to offer any rare disease patient to connect with others.

Knowing about other rare and very rare disease patients is not easy without proper registry and coding. The only point, where the knowledge about patients initially exists, is at their caring experts and their networks. Indicating patient organizations or other patients to newly diagnosed patients as part of the therapy should be state of the art for patient friendly care.

**Status**

Almost all very rare disease patients, which finally reached our national rare disease community und umbrella organization for rare diseases, found their way with google.  
Those without national patient organizations found some connection on/with facebook, if they did. Some found contacts on [diseasemaps.org](http://www.diseasemaps.org), while rare connect played no significant role.

In Austria, from all our ERN members and partners, only 2 individual doctors answered the question on patient connection or indication of patient organizations positive during their application.

**Demand**

ERNs claim their role as experts and examples in patient centered good care.

Connecting patients as part of good care is not an option, it is a mandatory requirement of patient friendly and patient centered care.

Every ERN member or ERN partner should confess to connect newly diagnosed patients or – at least – indicate directions how to find others, if there are no other patients or patients with similar disease at that ERN location.