# Sažetak projekta

# Ciljevi projekta

U okviru Projekta su izučavani molekularnogenetički markeri značajni za dijagnozu, prognozu i terapiju odabranih retkih bolesti što je rezultovalo boljom stratifikacijom pacijenata, individualizacijom terapije i racionalizacijom u oblasti zdravstvenog sistema. Formirane su i biobanke za mnoge druge retke bolesti, jer je Projekat omogućio istinsko povezivanje genetičara i lekara, te su informacije i svest o značaju formiranja biobanki stigle do mnogih zdravstvenih radnika. Tako je broj retkih bolesti za koje postoje biobanke dostigao 40. Ukupan broj uzoraka u biobankama je prevazišao broj od 2000.

# Ciljevi podporjekta

U okviru podprojekta istražuju se društvene konsekvence etički dozvoljenog i nedozvoljenog, kada su u pitanju retke bolesti. Objašnjavaju se fundamentalni pojmovi koji se primenjuju u odlučivanju i evaluaciji najvažnijih postupaka u pitanjima života i smrti. Mnoga pitanja koja su u drugim oblastima života pokrivena kvalitetnim pojmovima i kriterijumima evaluacije kod retkih bolesti tek treba da se ustanove u okviru mreže velikog broja parametara koji se protežu od toga šta je medicinski moguće, preko toga kako to opravdati (s obzirom na pitanje pravednosti i distributivne pravde), do toga kako to pretočiti u pravne norme sa različitim društveno-političkim i socio-psihološkim konsekvencama. Posebno su izučavani fenomeni dostupnosti terapije u odnosu na prava pacijenata i nejednakosti u zdravlju u vezi sa retkim bolesti.

Ključne reči: retke bolesti, orfan lekovi, moralno prihvatljivo, bioetika, moralne konsekvence, moralno dozvoljeno, distributivna pravda, koncept retkosti.

# Ključni rezultati

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