

Table SI. Domains based on the children's free comments in one of the questionnaires, describing the burden of the disease

Domain	Examples of phrases and adjectives used in the comments
Hygiene	Smelly, glossy, disgusting, dripping
Social contact	Discomfort when meeting new people, avoiding important situations in life, tough to go to school
Self-esteem	Uncomfortable, ashamed, panicking
Impact on clothing	Extra shirt, stains, frequent change of clothes, certain colours used, ruined shoes
Physical contact	Hold hands, play with friends, hugging, sexual relations
Physical activity	Less physical effort
Pattern of movement	Raise of hands, walks with the arms straight along the sides, does not sit on plastic chairs
Practical impact	Affects school work, smudged grip, frequent showering, stains on surfaces/paper
Misinterpretation	Affects school grades, seems stressed, seems insecure, seems rude
Somatic impact	Cold hands/feet, eczema, fungus infection, worsened skin disease