

Supplementary Fig. S1. Study design overview.

Supplementary Table S1. Current treatments of crFMF, MKD/HIDS and TRAPS patients.

Variable	FMF	MKD/HIDS	TRAPS	HPFs
Treatment N (%)				
Anakinra + other	0 (0.0)	1 (14.3)	0 (0.0)	1 (1.3)
Anakinra monotherapy	2 (3.5)	3 (25.0)	2 (16.6)	7 (9.2)
Canakinumab monotherapy	0 (0.0)	0 (0.0)	2 (16.6)	2 (2.6)
Canakinumab + other	0 (0.0)	0 (0.0)	2 (16.6)	2 (2.6)
Colchicine + anakinra + other*	5 (8.8)	1 (14.3)	1 (8.3)	7 (9.2)
Colchicine + canakinumab	4 (7.0)	0 (0.0)	0 (0.0)	4 (5.3)
Colchicine + golimumab + other	1 (1.8)	0 (0.0)	0 (0.0)	1 (1.3)
Colchicine + other	12 (21.1)	0 (0.0)	0 (0.0)	12 (15.8)
Colchicine monotherapy	31 (54.4)	0 (0.0)	0 (0.0)	31 (40.8)
No treatment [†]	1 (1.8)	2 (28.6)	0 (0.0)	3 (3.9)
Other*	1 (1.8)	0 (0.0)	5 (41.7)	6 (7.9)
Total patients on treatment (N)[‡]				
Satisfaction with how well treatment works	56 (100.0)	2 (100.0)	10 (100.0)	68 (100.0)
Extremely dissatisfied	5 (8.9)	0 (0.0)	1 (10.0)	6 (8.8)
Dissatisfied	6 (10.7)	0 (0.0)	2 (20.0)	8 (11.8)
Neutral	16 (28.6)	1 (50.0)	1 (10.0)	18 (26.5)
Satisfied	24 (42.9)	1 (50.0)	4 (40.0)	29 (42.6)
Extremely satisfied	5 (8.9)	0 (0.0)	2 (20.0)	7 (10.3)
Burden of mode of treatment				
Extremely inconvenient	7 (12.5)	0 (0.0)	0 (0.0)	7 (10.3)
Inconvenient	6 (10.7)	2 (100.0)	3 (30.0)	11 (16.2)
Neutral	14 (25.0)	0 (0.0)	0 (0.0)	14 (20.6)
Convenient	19 (33.9)	0 (0.0)	6 (60.0)	25 (36.8)
Extremely convenient	10 (17.9)	0 (0.0)	1 (10.0)	11 (16.2)

*Other treatments include NSAID, omeprazole, atomoxetine and metformin.

[†]These patients did not receive any treatment.

[‡]8 Patients were excluded as they believed they were not currently taking any treatment.

Supplementary Table S2. The area of the body experiencing pain/symptoms relating to their disease*.

Flare status	FMF		MKD/ HIDS		TRAPS		HPFs	
	OFF N (%)	ON N (%)	OFF N (%)	ON N (%)	OFF N (%)	ON N (%)	OFF N (%)	ON N (%)
Body area pain or other symptoms								
Head	124 (5.9)	292 (5.7)	51 (18.1)	59 (14.5)	3 (1.3)	24 (16.2)	178 (6.7)	375 (6.6)
Neck	41 (1.9)	58 (1.1)	11 (3.9)	22 (5.4)	32 (13.4)	0 (0.0)	84 (3.2)	80 (1.4)
Chest	73 (6.8)	168 (3.3)	7 (2.5)	10 (2.5)	1 (0.4)	4 (2.7)	81 (3.1)	182 (3.2)
Stomach	144 (7.3)	367 (7.2)	21 (7.5)	34 (8.3)	14 (5.9)	83 (56.1)	179 (6.8)	484 (8.5)
Shoulder	84 (4.0)	230 (4.5)	12 (4.3)	65 (15.9)	0 (0.0)	0 (0.0)	96 (3.6)	295 (5.2)
Upper arm	178 (5.9)	92 (1.8)	26 (9.3)	10 (2.5)	6 (2.5)	0 (0.0)	210 (7.9)	102 (1.8)
Elbow	125 (2.8)	323 (6.4)	11 (3.9)	19 (4.7)	2 (0.8)	37 (25)	138 (5.2)	379 (6.6)
Lower arm	60 (3.4)	230 (4.5)	6 (2.1)	11 (2.7)	16 (6.7)	0 (0.0)	82 (3.1)	241 (4.2)
Wrist	75 (8.4)	196 (3.9)	18 (6.4)	0 (0.0)	0 (0.0)	0 (0.0)	93 (3.5)	196 (3.4)
Palm	156 (2.0)	292 (5.7)	13 (4.6)	10 (2.5)	18 (7.6)	0 (0.0)	187 (7.1)	302 (5.3)
Hip	42 (5.8)	151 (3.0)	5 (1.8)	38 (9.3)	0 (0.0)	0 (0.0)	47 (1.8)	189 (3.3)
Thigh	126 (3.5)	382 (7.5)	23 (8.2)	29 (7.1)	66 (27.7)	0 (0.0)	215 (8.1)	411 (7.2)
Knee	246 (12.0)	571 (11.2)	29 (10.3)	65 (15.9)	28 (11.8)	0 (0.0)	303 (11.5)	615 (10.8)
Lower leg	207 (8.9)	528 (10.4)	16 (5.7)	15 (3.7)	16 (6.7)	0 (0.0)	239 (9.0)	643 (11.2)
Ankle	256 (25.8)	694 (13.7)	11 (3.9)	10 (2.5)	31 (13.0)	0 (0.0)	298 (11.3)	704 (12.3)
Foot	189 (11.6)	509 (10.0)	21 (7.5)	11 (2.7)	5 (2.1)	0 (0.0)	215 (8.1)	520 (9.1)

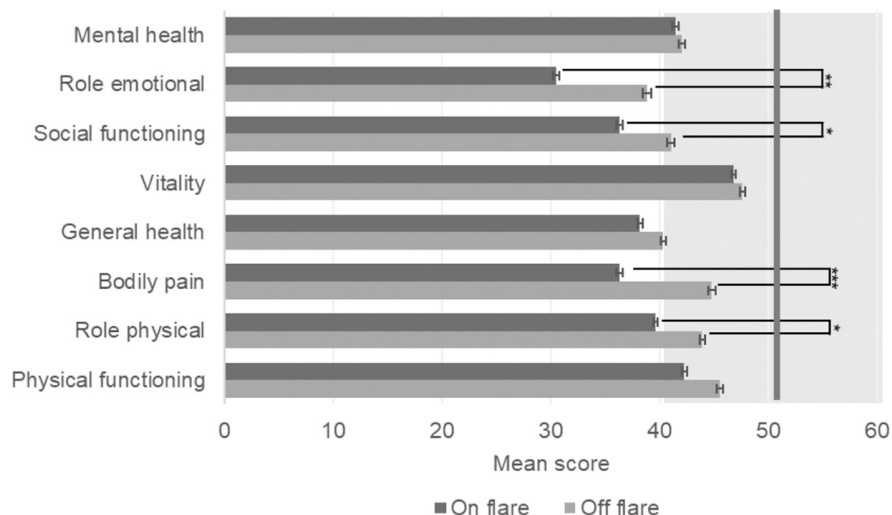
*More than one area could be selected per patient.

Supplementary Table S3. Patient and caregiver education and working status.

Variable	FMF N (%)	MKD/ HIDS N (%)	TRAPS N (%)	HPFs N (%)
Child and adolescent patient's school attendance status				
Yes, full time	21 (72.4)	7 (70.0)	1 (50.0)	29 (70.7)
Yes, part time	2 (6.9)	2 (20.0)	1 (50.0)	5 (12.2)
No, at least partially due to their condition	3 (10.3)	0 (0.0)	0 (0.0)	3 (7.3)
No, for other reasons	3 (10.3)	1 (10.0)	0 (0.0)	4 (9.8)
Adult patient's current school attendance status				
Yes, full time	4 (14.3)	0 (0.0)	1 (20.0)	5 (14.3)
Yes, part time	1 (3.6)	0 (0.0)	0 (0.0)	1 (2.9)
No	23 (82.1)	2 (100.0)	4 (80.0)	29 (82.9)
Patient's working status*				
Working part-time	9 (32.1)	0 (0.0)	2 (40.0)	11 (31.4)
Working full-time	10 (35.7)	0 (0.0)	2 (40.0)	12 (34.3)
Volunteering part-time	2 (7.1)	0 (0.0)	1 (20.0)	3 (8.6)
Volunteering full-time	2 (7.1)	0 (0.0)	0 (0.0)	2 (5.7)
Unable to work	3 (10.7)	0 (0.0)	0 (0.0)	3 (8.6)
Unemployed	2 (7.1)	1 (50.0)	0 (0.0)	3 (8.6)
Stay at home parent	2 (7.1)	1 (50.0)	1 (20.0)	4 (11.4)
Retired	1 (3.6)	0 (0.0)	0 (0.0)	1 (2.9)
The reason for not working full-time at least partially due to their condition**	10 (35.7)	1 (50.0)	2 (40.0)	13 (37.1)
Caregiver's working status*				
Working part-time	13 (44.8)	3 (30.0)	0 (0.0)	16 (39.0)
Working full-time	10 (34.5)	4 (40.0)	2 (100.0)	16 (39.0)
Volunteering part-time	0 (0.0)	1 (10.0)	0 (0.0)	1 (2.4)
Volunteering full-time	1 (3.4)	0 (0.0)	0 (0.0)	1 (2.4)
Unable to work	1 (3.4)	0 (0.0)	0 (0.0)	1 (2.4)
Stay at home parent	1 (3.4)	0 (0.0)	0 (0.0)	1 (2.4)
Retired	7 (24.1)	4 (40.0)	0 (0.0)	11 (26.8)
The reason for not working full-time at least partially due to their condition**	14 (82.3)	5 (83.4)	0 (0.0)	19 (82.6)

*More than one answer could be selected by each patient; one FMF patient also attended full-time school.

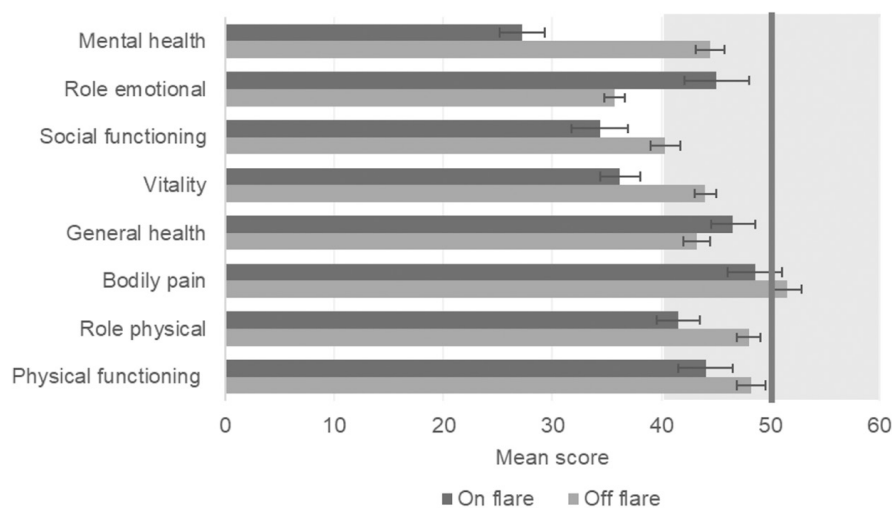
**Includes working part-time and stay at home parents and those who do one of this as well as another working status.



Supplementary Fig. S2. SF12 scores for crFMF patients.

SF12 covers multiple health scales, ranging from mental to physical functioning scale. Data calculated using an adjusted regression model and values shown as an average. The dark grey vertical line at 50 represents the average normed population score; the surrounding lighter grey box from 40-60 represents the standard deviation. Error bars represent SEM.

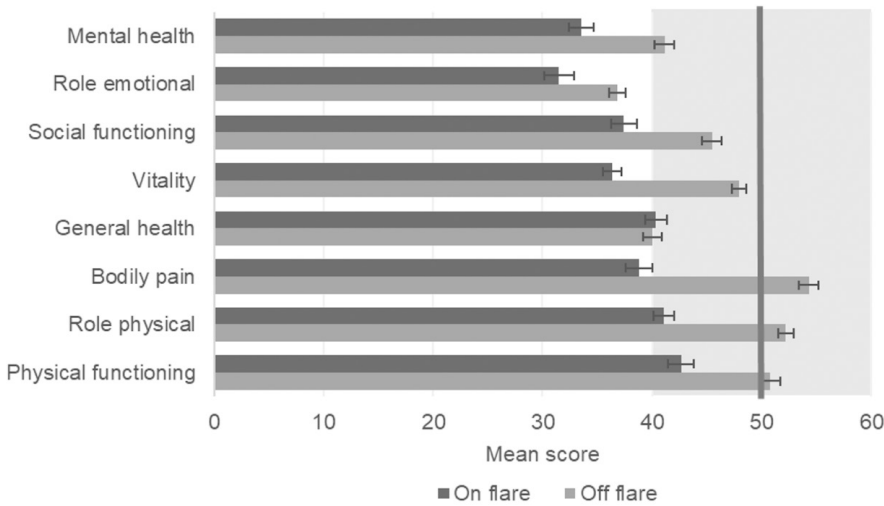
* $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$.



Supplementary Fig. S3. SF12 scores for MKD/HIDS patients.

SF12 covers multiple health scales, ranging from mental to physical functioning scale. Data calculated using an adjusted regression model and values shown as an average. The dark grey vertical line at 50 represents the average normed population score; the surrounding lighter grey box from 40-60 represents the standard deviation. Error bars represent SEM.

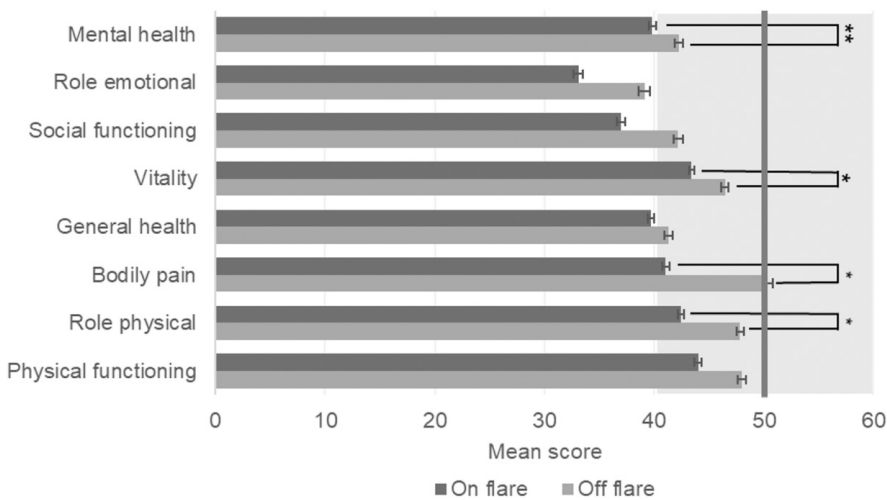
** $p \leq 0.01$.



Supplementary Fig. S4. SF12 scores for TRAPS patients.

SF12 covers multiple health scales, ranging from mental to physical functioning scale. Data calculated using an adjusted regression model and values shown as an average. The dark grey vertical line at 50 represents the average normed population score; the surrounding lighter grey box from 40-60 represents the standard deviation. Error bars represent SEM.

* $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$.



Supplementary Fig. S5. SF12 scores for All patients. SF12 covers multiple health scales, ranging from mental to physical functioning scale. Data calculated using an adjusted regression model and values shown as an average. The dark grey vertical line at 50 represents the average normed population score; the surrounding lighter grey box from 40-60 represents the standard deviation. Error bars represent SEM.

* $p \leq 0.05$; ** $p \leq 0.01$.