

Findings from what EF patients have posted in online forums

Data sources

A cohort of 386 patients was selected from around 450 diagnosed with, or believed to have, Eosinophilic Fasciitis (EF). The postings were in four online health forums with posting dates from 2010 to early December 2020. Selection criteria included the confidence in their diagnosis (MRI, biopsy, etc) and the data shared by the patient.

Demographics

About 70% of patients live in the USA but this only reflects the demographic of the forums not the global prevalence of the disease [1]. The female to male ratio of Eosinophilic Fasciitis patients posting online is about 2:1. There are more females in their 50s. Child patients diagnosed with EF are nearly all female [2].

[1] [L00501 List PATIENT statistics for excel.14.Countries.upload.pdf](#)

[2] [L00501 List PATIENT statistics for excel.01.AgeGroups.upload.pdf](#)

Prognosis

Most EF patients reach remission, if not full recovery, within 1-3 years [2]. Early diagnosis improves outcomes [3] but the patient's general state of health also has an influence [1]. Patients who are proactive about therapies, exercise and diet generally recover sooner than those who rely only on the drugs [4].

[1] [L00305 List PATIENT outcomes.exec.sql.ages_all.upload.txt](#)

[2] [L00501 List PATIENT statistics for excel.03.YearsToCurrentState.upload.pdf](#)

[3] [L00501 List PATIENT statistics for excel.04.MonthsToDiagnose and CurrentState.upload.pdf](#)

[4] [L00501 List PATIENT statistics for excel.07.Treatments and States.upload.pdf](#)

Symptoms

Patients complain of edema, induration, loss of flexibility, pain, fatigue. The body parts most often mentioned are legs, arms, hands [1]. Women complain of a lumpy appearance to their skin and many women mention a swollen abdomen (which 3 out of 4 believe is the disease and 1 out of 4 believe is an effect of Prednisone).

[1] [L00306 List PATIENT statistics.sql.11.CountSymptoms.upload.txt](#)

Treatments

The drugs most prescribed are Prednisone and Methotrexate, taken together [1]. This combination gets the most credit from patients [2] but it should be balanced against patients gradually recovering regardless of treatment. Studies have found that high dose infusions of methylprednisolone at the start of treatment improve outcomes but there is not yet enough forum data to confirm this. What the data does show is that patients receiving only Prednisone/Prednisolone with Methotrexate do better than average especially when not burdened by other health issues [3].

[1] [L00501 List PATIENT statistics for excel.11.CountDrugs.upload.pdf](#)

[2] [L00501 List PATIENT statistics for excel.12.CountCredits.upload.pdf](#)

[3] [L00305 List PATIENT outcomes.exec.sql.ages_all.upload.txt](#) (scroll to listing 11)

The tables below show average time to recover by age. When excluding the few chronic cases (exceeding 10 years) the average time to remission for most EF patients comes within 3 years. The recovery times for young patients vary more than the other ages. Recovery times for Females and Males are similar.

EF patients who recovered or improved (excluding chronic)				
	remission or recovered		improved only	
ages	patients	months	patients	months
0-15	12	47	5	14
16-30	31	29	10	17
31-40	40	35	23	29
41-50	23	35	23	22
51-60	41	34	36	21
61-80	19	36	24	28
ALL	166	35	121	24

Females				
	remission or recovered		improved only	
ages	patients	months	patients	months
0-15	10	49	4	16
16-30	20	28	5	17
31-40	23	31	11	26
41-50	14	32	15	26
51-60	35	34	27	23
61-80	13	38	22	28
ALL	115	34	84	25

Males				
	remission or recovered		improved only	
ages	patients	months	patients	months
0-15	2	35	1	6
16-30	11	31	5	16
31-40	17	39	12	32
41-50	9	41	8	16
51-60	6	36	9	17
61-80	6	34	2	17
ALL	51	36	37	21

Causes and triggers

EF patients do not know what causes their disorder but many suspect a genetic predisposition and there is evidence for this (eosinophilic disorders in the same family) [1]. The triggers most often cited by patients are stress, physical exertion, infection, surgery/injury/trauma, insect bites, toxin, allergies [2].

[1] [2020.Eosinophilic Fasciitis in Families.mogfitz.pdf](#)

[2] [L00306 List PATIENT statistics.sql.12.CountTriggers.upload.txt](#)

Other health conditions

The most often mentioned diseases/disorders that preceded or co-exist with their EF are:
Autoimmune: Localized scleroderma/morphea, Hyperthyroidism/Hypothyroidism [1].

Non-autoimmune: Arthritis, Allergies, Cancer, Diabetes, Osteoporosis [2].

[1] [L00306 List PATIENT statistics.sql.18.HavesAutoimmune.upload.txt](#)

[2] [L00306 List PATIENT statistics.sql.19.Haves.upload.txt](#)

Family diseases

The most often mentioned autoimmune diseases which EF patients have in their families: Eosinophilic disorders, Lupus, Psoriasis, Ulcerative colitis, Rheumatoid Arthritis [1].

[1] [L00306 List PATIENT statistics.sql.14.FamilyAutoimmune.upload.txt](#)

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