Who Does ES Affect? 

ES is ultra-rare, and estimated to affect fewer than 1,000 people in the U.S. annually. 

Although it can affect people of all ages and genders, ES is more likely to affect men and young adults.

ES occurs in two forms: 

1. Distal-type 
   - Classic form, typically affects teenagers and young adults 
   - Associated with more favorable survival rates 
   - Typically affects hands, forearms, feet and ankles

2. Proximal-type 
   - Rarer form, mainly affects older adults and is more aggressive 
   - Associated with less favorable survival rates 
   - Typically affects torso

ES is frequently misdiagnosed or diagnosed late because: 

• It’s rare (fewer than six new diagnoses per 100,000 people per year) 
• Looks harmless when it first forms 
• Often occurs in young adults in their 20s and 30s

Your doctor may do the following to make a conclusive diagnosis of ES: 

1. Physically examine the area 
2. Order a scan 
3. Biopsy (tissue sample) the area

Physical examination of the area or imaging tests may show a hard lump under the skin or elsewhere. Biopsy is the only way to definitively diagnose ES.

ES grows slowly and often painlessly, however it can cause pain for some people. ES is frequently mistaken for other conditions: 

• Infected wart 
• Wound that won’t heal 
• Upset stomach, menstrual cramps 
• 1 out of 5 patients with ES may experience pain

Early diagnosis of ES is key, as earlier treatment can result in more favorable outcomes.

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