



2026 marks 20 years of National Epidermolysis Bullosa (EB)* Awareness Week



Each year, **October 25-31** is recognized as National EB Awareness Week, a time to raise awareness and recognize the EB community. **This year marks a special milestone—it has been 20 years since Congress designated the last week of October as National EB Awareness Week in 2006.**

*FILSUEZ is for dystrophic and junctional EB wounds.

To recognize this milestone, here are 20 things you may not know about EB

- 1. The history of National EB Awareness Week goes back more than 40 years.** The observance was first nationally recognized in 1984, more than two decades before the 2006 Congressional recognition.
- 2. EB is known as “The worst disease you’ve never heard of.”** The nickname reflects the severe pain, lifelong challenges, and rarity of the condition, while highlighting the need for greater public awareness and research.
- 3. EB is often called “butterfly skin.”** People with EB have skin so fragile that it’s compared to the delicate wings of a butterfly. Even minor friction can cause painful blisters and wounds.
- 4. EB can be caused by changes in many different genes.** These genetic changes can affect proteins that help give skin its strength and stability.
- 5. EB occurs in every race and affects both males and females.** The condition is found worldwide and is not linked to ethnicity or gender.
- 6. Some types of EB affect proteins that help hold the skin together.** When these proteins are missing or do not work properly, layers of skin can separate more easily and cause blisters.
- 7. There are four main types of EB,** including EB simplex, junctional EB, dystrophic EB, and Kindler EB.
- 8. EB can be passed down in different ways.** Depending on the type of EB, a person may inherit the genetic change through a dominant or recessive pattern.
- 9. Wound care is an important part of living with EB.** Consistent wound care can help protect fragile skin, manage blisters and wounds, and help reduce the risk of complications.
- 10. Simple everyday activities can cause injuries.** Walking, hugging, brushing teeth, getting dressed, or holding a pencil can create blisters for someone with severe EB.

Indication

What is FILSUEZ (birch triterpenes) topical gel for?

FILSUEZ is a prescription medicine used on the skin to treat wounds that may happen with dystrophic and junctional epidermolysis bullosa (EB) in adults and children 6 months of age and older.

It is not known if FILSUEZ is safe and effective in children younger than 6 months of age.

Important Safety Information

What is the most important safety information I should know?

FILSUEZ may cause a serious side effect of allergic reactions.

Allergic reactions and skin reactions to FILSUEZ may include the following symptoms: red itchy bumps (hives), skin rash, redness or itching. If you get any of these symptoms, stop using FILSUEZ right away and call your healthcare provider.

What are the possible side effects of FILSUEZ?

The most common side effect of FILSUEZ is application site reactions, such as pain and itchy skin.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088

Please see additional **Important Safety Information** on page 2.

Please see **Full Product Information** and **Patient Information**.



11. **Approximately 500,000 people** around the world are estimated to be living with EB.
12. **People with EB may be at risk for infection.** Good wound care, clean hands, and proper nutrition can help reduce the risk of wounds becoming infected.
13. **Wound care can take hours.** Some people with EB or their caregivers may spend more than 2 hours daily changing bandages and treating wounds.
14. **What someone wears can make a difference.** Soft, non-irritating clothing may help reduce friction and protect fragile skin from injury.
15. **Sudden changes in temperatures can exacerbate symptoms,** so maintaining a stable environment is important.
16. **Staying hydrated can be especially important for people with EB.** Wounds and other complications of EB may increase fluid needs, making adequate hydration an important part of care.
17. **Regular follow-up is an important part of EB care throughout life.** Healthcare teams can monitor the condition, check overall health, and identify and manage complications.
18. **Some people with EB may need surgery.** Depending on the type and severity of EB, procedures may be needed to manage certain complications.
19. **EB can be linked to changes in at least 21 different genes.** These genetic differences can help explain why EB can look different from person to person.
20. **Hope has never been greater.** While there is still no cure for EB, today's research has moved from simply managing symptoms to repairing skin and addressing the underlying cause of the disease. Families have treatment options today that weren't available just a few years ago.

Take awareness beyond National EB Awareness Week

Share what you know about EB with friends, family, and your community to help more people understand the condition and the experiences of those affected by it.

Learn more about [FILSUVEZ](#), a treatment option for dystrophic and junctional EB.

Important Safety Information (cont'd)

How should I use FILSUVEZ?

See the detailed "Instructions for Use" that comes with FILSUVEZ for information on how to apply FILSUVEZ.

Use FILSUVEZ exactly as your healthcare provider tells you to use it.

The tube of FILSUVEZ is for one-time use only. After the tube has been opened, apply the gel right away. Throw away any remaining gel and the tube after use.

Do not use around or get FILSUVEZ in the eyes, or mucous membrane areas, examples are mouth, vagina or anus.

If you get FILSUVEZ in your eyes or mucous membrane area, rinse with clean water right away. Contact your healthcare provider if you have any discomfort.

If the wounds you are treating with FILSUVEZ become infected, **stop treatment** and contact your healthcare provider. Signs or symptoms of infection may include the wound becoming red, warm, swollen, painful or drains yellow or greenish fluid (pus).

Please see [Full Product Information](#) and [Patient Information](#).



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PP-RA-02492 V1.0

Filsuvez®
(birch triterpenes) topical gel