

Important updates for adults living with Osteogenesis Imperfecta from the Brittle Bone Society Medical Advisory Board



Authors

BBS Medical Advisory Committee and Professor S Ralston

Release date

15th May 2026

| | |
|---|---|
| 1. Title..... | 2 |
| 2. What is this about? | 2 |
| 3. Can you tell me more about the trial? | 2 |
| 4. What could this mean for adults with OI?..... | 2 |
| 5. Do we know why did the medication not work? | 2 |
| 6. Which types of medications were tested?..... | 3 |
| 7. I have been recommended to start one of these medications, what should I do? | 3 |
| 8. I am already on one of these medications, what should I do? | 3 |
| 9. I am on an osteoporosis medication called denosumab or Prolia which is not on the list, what should I do?..... | 3 |
| 10. My child is on a bisphosphonate, what will happen? | 3 |
| 11. I still have questions, what should I do? | 4 |

1. Title

Important update for adults living with Osteogenesis Imperfecta from the Brittle Bone Society Medical Advisory Board

2. What is this about?

A new trial for the treatment of adults with OI has been published in a major medical journal. This is the first trial to test the benefit of osteoporosis treatments in adults with OI. The trial has shown certain osteoporosis treatments do not reduce fractures. The results of the trial have been discussed with experts who are part of the Brittle Bone Society Medical Advisory Board and they have agreed the trial results are clear and have important implications for adults living with OI.

3. Can you tell me more about the trial?

The trial is called Topaz and was led by Professor Ralston from the University of Edinburgh, UK. The trial compared standard care with 2 years of teriparatide followed by a single dose of zoledronate over 8 years. 350 adults were involved in the trial recruited by 27 centres in the United Kingdom and Europe. Adults in the trial knew which treatment they were on and were followed up to measure their bone density, the number of broken bones diagnosed by x-ray, and the number of broken bones reported by the patient, even though x-rays had not been performed

The trial found that 2 years of teriparatide then zoledronate significantly improved bone density but this did not change how many adults broke a bone, including no difference in broken bones of the spine.

4. What could this mean for adults with OI?

This is the first and largest study to test the potential benefit of using these medications in adults with OI and is the best evidence we have to guide treatment. It is clear that these drugs improve bone density but they do not make the bones stronger. The improvement in bone density maybe useful in certain situations but should not be used to reduce the risk of fracture.

5. Do we know why did the medication not work?

Doctors have used osteoporosis medications for adults with OI for many years, assuming that increases in bone density would be beneficial in preventing fractures. However up until now this theory has never been tested in people with OI. Both osteoporosis and OI make bones weaker, so they are more likely to break. However, OI is not osteoporosis. In osteoporosis the bones are weak because there is less bone but the bone is normal. In patients with OI, the bone itself is abnormal. This trial has shown this difference means that these treatments that work in osteoporosis do not work in OI for adults.

6. Which types of medications were tested?

The trial tested drugs called bisphosphonates and teriparatide.

There are many different types of these drugs and we believe the Topaz trial findings are generalisable to:

1. Alendronate or alendronic acid or fosamax
2. Risedronate or risedronic acid or actonel
3. Ibandronate or ibandronic acid or bonviva.
4. Pamidronate
5. Zoledronate or zoledronic acid or aclstea.
6. Teriparatide or forsteo
7. Abaloparatide or Elndayo.

7. I have been recommended to start one of these medications, what should I do?

We recommend you do not start till you have had a chance to discuss the benefits vs risk of treatment with your doctor. Your doctor may not be aware of the results of the Topaz study and they can find more information about the trial on the [BBS website](#).

8. I am already on one of these medications, what should I do?

There is no need to stop taking your medication before you see your medical team. As more medical teams learn of the trial results, you may be called up to be reviewed sooner. If you do not have an upcoming appointment with your medical team then please ask your GP to refer to the nearest hospital centre. A list of hospitals in the expert network can be found on the [BBS Website](#).

9. I am on an osteoporosis medication called denosumab or Prolia which is not on the list, what should I do?

Denosumab is also a drug that is used in osteoporosis but works in a very different way to other osteoporosis medicines. However, like teriparatide and zoledronic acid denosumab increases bone density and based on the TOPAZ results, hence denosumab is also unlikely to be effective at preventing fractures. **Because of the way denosumab works, it is very important that denosumab is not stopped without discussing with a bone specialist and you continue to have your denosumab injections on time in the meantime.** We are working on a plan on what to advise.

10. My child is on a bisphosphonate, what will happen?

This trial was only conducted in adults and the duration of treatment with bisphosphonate was limited. We do not believe that the results are generalisable to children with OI whose skeleton is growing. Some trials have shown evidence of fracture reduction with

bisphosphonates in children with OI. We recommend that if your child is on a bisphosphonate this should continue. Trials of other medicines which increase bone density are being conducted in children with OI to see if they can prevent fractures. The results of these trials have not yet been reported but the BBS will provide an update when these results are available.

11. I still have questions, what should I do?

You can ask your usual medical care team.

You can also contact us at the Brittle Bone society at admin@brittlebone.org for more information.