

FOR PARENTS & CAREGIVERS — ER EMERGENCY REFERENCE

If CPS Questions You While Your OI Child Is in the ER

OI (brittle bone disease) is frequently mistaken for child abuse. You have the right to advocate clearly and calmly for your child. Keep this sheet with your child's medical records at all times.

STAY CALM & COMMUNICATE CLEARLY

- 1 Stay calm and cooperate.** Staff are legally required to investigate unexplained fractures to protect children. Your composure — not defensiveness — is your most powerful tool.
- 2 State your child's diagnosis immediately.** Say: "My child has Osteogenesis Imperfecta — brittle bone disease. Their bones fracture from minor force that would not injure a typical child."
- 3 Point out your child's visible OI features:** blue-tinted whites of the eyes, translucent teeth, very loose joints, or small stature. These are recognized clinical signs.
- 4 Do not sign anything you don't understand.** Ask to read every document carefully and ask what each one means before signing.

DOCUMENTS & RECORDS TO HAVE READY

- 5 Bring all OI documentation:** diagnosis letters, genetic test results, imaging or radiology reports, or any discharge summary that mentions OI or brittle bone disease.
- 6 Have your OI specialist's emergency number ready** and ask staff to call them directly. A specialist's voice carries significant clinical weight.
- 7 Have names and numbers of all previous treating hospitals.** Records can be requested quickly to establish the history of OI care.
- 8 If you or the other parent has OI, say so** and ask that your records be noted. Most children with OI inherit it from a parent — family history is medically critical.
- 9 If siblings have OI or prior unexplained fractures, share that history.** A pattern of fragile bones in the family supports a genetic condition, not abuse.
- 10 Keep a written log throughout.** Note names of staff who speak to you, times, and what was said. This record may matter later.

REQUEST THESE FROM THE MEDICAL TEAM

- 11 Ask that a geneticist, pediatric orthopedist, or bone specialist be consulted** before any conclusions are drawn. Do not accept a CPS referral as the only path forward.
- 12 Request genetic or collagen testing** if no prior diagnosis exists. A skin biopsy or DNA blood test can confirm OI in most cases.
- 13 Know that a negative genetic test does NOT rule out OI.** Standard panels miss recessive forms. If initial results are negative, ask for a comprehensive gene panel.
- 14 Ask whether the hospital has a patient advocate** who can serve as a neutral party between your family and the medical or CPS team.

IF CPS INVOLVEMENT ESCALATES

- 15 Contact a family law attorney early.** Not because you've done anything wrong — you and your child deserve proper legal representation if this escalates.
- 16 Call the OI Foundation (1-800-981-2663).** They can provide medical fact sheets to hand directly to ER staff and connect you with support resources.
- 17 Reach out to OI parent community groups.** Other families have navigated this exact situation and can provide guidance and support in real time.

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Important: About 25% of children with OI are born with no family history — a new gene mutation. The absence of OI in parents does NOT disprove your child's diagnosis.

KEY RESOURCES TO FILL IN NOW — BEFORE AN EMERGENCY

OI Foundation helpline	1-800-981-2663 oif.org
My child's OI specialist	Name & number: _____
Previous treating hospital	Name & number: _____
Family law attorney	Name & number: _____