English

I have osteogenesis imperfecta (OI, brittle bones). This means that my bones are fragile. OI not only affects the skeleton but the connective tissue in general. Please, consult me/my parents/my companion before you move, transport, examine or treat me; follow my/their directions on how to handle me safely.

We wish to remind you about the following

- In osteogenesis imperfecta fractures can occur easily, or even spontaneously.
- Symptoms of fractures are not always obvious; pain often indicates a fracture.
- Just looking for signs of fractures, e.g. abnormal mobility or crepitation, can cause a fracture.
- The safest way to determine or exclude a fracture is by X-ray examination (see below).
- As a rule fractures are painful.
- In case of pain, even without a diagnosed fracture, treatment should, sometimes, be the same as for a fracture.
- Adequate analgesia is advisable, in children as well as adults.
- Dosing for medications and anesthesia should be based on the person’s size rather than age.
- An analgesic and/or a night sedative are recommended the first few days after a fracture.
- Lightweight materials are preferred for immobilisation.
- Patients with OI should be mobilised as soon as possible.
- Please, contact the treating specialist when hospitalisation or surgery is necessary.
- Many patients with OI have a hearing problem.

X-ray examination

- In osteogenesis imperfecta the bones may be demineralised. Lower radiation intensity is usually appropriate (as in osteoporosis) to avoid needless repeat films.
- Excessive movements and needless lifting should be avoided.
- Patients or their parents/companions are often experienced by previous examinations. They can be helpful in finding the right position for X-rays to be taken.
- A lead shield for the reproductive organs should be used.

Surgery and Anaesthesia

- Carefully transfer the person/patient to and from the operating table, supporting him/her well.
- Be aware of existing deformities or contractures when positioning the person/patient on the operating table.
- Bend the head gently backwards for intubation, minimizing the risk of fracturing cervical vertebrae; be aware of the vulnerable mucosa of the trachea. The teeth are often fragile as well.