

Facts about Osteogenesis Imperfecta

Know Your OI: A Basic Health History

Introduction

It is important for adults who live with a lifelong medical condition such as OI to have access to their medical history information. Both electronic and paper records can serve the purpose. This document is an outline of information typically needed by an adult who has OI. A form like this can:

- Help parents share health information with their teenager.
- Help adults summarize their own OI health history.

Adults do not need to keep detailed records about every childhood fracture or illness.

In some cases, children's hospitals will provide a summary of surgeries and treatments when the young adult moves into the adult care system. This can be a good place to start.

Your personal health profile will continue to evolve over time. Setting up **an easy-to-use system** to keep track of test results, hospitalizations and treatments is very beneficial. Your primary care doctor or insurance company may have suggestions for appropriate apps or websites. Some people keep pictures of health forms on their cell phones. If you opt to store health information directly on your cell phone, be sure to regularly update and use the password and security functions.

Important Information to Keep

Healthcare Providers

- Maintain a list of all of the doctors you see and their contact information.
- This will make it easier to locate them if you need details about a treatment.

Health Insurance

- You will need the exact name and policy number(s) of your current insurance.
- It is a good idea to review coverage at least once a year.
- Also keep a record of your insurance history. You need the names of each company, the policy numbers and the dates you were covered. In many cases it is important to be able to show that you have always been covered.

Orthotics, Equipment, and Medicines

- List the model number, manufacturer and dealer of any equipment you currently use.
- Note where items can be repaired.
- Carry an up-to-date list of all medicines and dietary supplements you currently use.

Family Health Information

- People who are affected by OI are advised to keep a list of relatives who have OI.
- It is a good idea to learn about your family health history. OI does not rule out being at risk for the other health issues that affect adults or that can run in families such as heart disease or cancer.

Fill out only the sections that apply. Use extra pages if necessary.

Diagnosis

- When _____ OI type or mutation (If known) _____
- How:
clinical exam _____ skin/collagen biopsy _____ DNA analysis _____

Drugs – List all bone related drugs such as pamidronate.

Drug name	Begin/End Date	Dose
Bisphosphonate (pamidronate)		
Bisphosphonate (zoledronic acid)		
Forteo		
Prolia (denosumab)		
Other _____		

Fracture & Osteotomy History – Check all major fractures and site of osteotomies. If a bone was broken more than once list the most recent. Include rod information for any rods that are still in use.

Location		Date(s)	Type of Rod	Plate/Screw	Non-Union
Femur	Right Femur Left Femur				
Tibia	Right Tibia Left Tibia				
Arm	Right Humerus Left Humerus				
Spine Fractures					
Pelvis					

Other Orthopedic Questions

Tendon and/or Ligament Injuries – list any recurring injuries or injuries that required medical attention.

Joint Injury – Check all that apply

Location	Date	Left/Right	Treatment
Knee			
Ankle			
Wrist			
Shoulder			

Spine Health – Mark any spine curves or fractures you’ve been diagnosed with & note treatment

Spine Curves/Fractures	Treatment
Scoliosis	
Kyphosis	
Spondylosis	
Vertebral Fractures	

Other Orthopedic Surgeries – Mark other OI related surgeries

Spine Curves/Fractures	Treatment

Chest – pectus correction	
Hips – acetabular protrusion	
Leg length difference	
Leg or arm bowing	

Other OI Related Health Questions

OI Related Testing -- list date of latest test and a summary of results

	Date/Latest	Results
Bone Density Test		
Echocardiogram		
Pulmonary Function Tests		

Basilar Impression-- Provide diagnosis and treatment information if this is part of your history

Breathing – Respiratory Function

- I have been diagnosed with Asthma
- I have been diagnosed with Sleep Apnea

Dental Care – Mark any of the following that apply

- I have been diagnosed with Dentinogenesis Imperfecta (DI – Fragile Teeth)
- I have been diagnosed with TMJ
- I have been diagnosed with osteonecrosis of the jaw
- I have the following: veneers _____, caps_____, a “partial,” _____ dentures_____

Gastrointestinal Problems – Describe any current problems with constipation or GERD

Hearing—Mark all that apply

- I was diagnosed with hearing loss at age_____
- I use the following type of hearing aids _____
- I have had a stapedectomy
- I have had a cochlear implant

Heart—Mark all that apply

- I have been diagnosed with a heart valve problem
- I have been diagnosed with high blood pressure (hypertension)
- I have a family history of relative with and without OI who have heart problems

General Health Information

Allergies _____

Childhood illnesses _____

Immunizations _____

- Pneumonia Vaccine PCV13 Date** _____
- Pneumonia Vaccine PPSV23 Date** _____

Date of latest flu shot

Women’s Health

- Menstruation began at age** _____
- I have been pregnant** _____ **times**