Shriners Hospitals for Children® — Canada

SUNNAAS REHABILITATION HOSPITAL

TRS National Resource Centre for Rare Disorders

Individualized School Plan for Optimal Inclusion of Students with Osteogenesis Imperfacta (OI)

Shriners Hospitals for Children®—Canada

Table of Contents

Overview of Individualized School Plan 3

Medical History 4

Identification Card 5

Emergency Contact Information 5

Fracture Response Plan 5-7

Mobility and Environmental Considerations 7-8

Wheelchair Transfers 8

Toileting 9

Physical Activity 10-11

Fieldtrips 12

Transportation 12

School Evacuation Plan 13

Seating Considerations 13

Scholarly Considerations 14

Assent and Consent 14

Authorization 15

Annual Renewal 15

Appendices 16

Appendix 1. Identification and Passport 16

Appendix 2. List of Suggested Items to be Included in a OI Support Kit 17

Appendix 3. List of Adapted Activities for Physical Education 18

Appendix 4. List of Adapted Activities for Lunchtime, Recess, Extracurricular Activities and After School Care 19

Appendix 5. Transportation Sign to be Posted on School Bus and Other Vehicles 20

Revised December 2022

Shriners Hospitals for Children® — Canada

Student name _____

OVERVIEW OF INDIVIDUALIZED SCHOOL PLAN

What is Osteogenesis Imperfecta (OI)?

Osteogenesis Imperfecta, also known as the brittle bone disease, is a genetic disorder of the collagen that causes the bones to be more fragile. This rare disorder is characterized by an increased risk of bone fractures, bone deformities, and ligament laxity. Therefore, it is important to provide students with OI necessary accomodations to ensure optimal inclusion at school.

OI is categorized in different types, ranging from very mild to severe. The specific medical problems a student develops depends on the severity type. The characteristic features of OI vary greatly from person to person, even among people with the same type of OI. Hence, it is important to follow an individualized care plan to address the need of each student. Also note that people with OI do not present with cognitive deficits associated with this condition.

Who is this care plan for?

This individualized care plan is developed for students with OI, ranging from kindergarten to the last year of high school. This plan is to be used by school personnel (e.g. teachers, school nurse and support staff) in collaboration with the student, their parents, and healthcare professionals.

What is included in this care plan?

This plan includes safety recommendations and precautions for use in the classrooms, hallways, bathrooms, physical education courses, schoolyards and field trips. This plan also includes the protocols for emergency response situations and suspected bone fractures.

If you have any further questions regarding the recommendations and protocols listed in this document, do not hesitate to contact:

Name: _____

Relationship with student: _____

Email: _____

Phone number: _____

Inclusivity

In all situations, inclusion with classmates is key for psychosocial wellbeing and self-esteem. We strongly recommend that the student be included as much as possible in all school activities. Their integration and participation are important for their self-worth and development as long as the recommendations and precautions are followed, the student has every opportunity to interact and contribute positively to school life just as any of their peers.

Listen to the student, as they know themselves better than anyone, and engage them in discussions about their needs, concerns, strengths and limitations. Additionally, a young child with OI may be of smaller stature than their peers. This is a physical attribute of OI. It is important to be mindful of this attribute to address and engage with the student in an age-appropriate manner and not by their physical stature.

Student name _____

MEDICAL HISTORY

Name of student: _____

Date of birth: _____ Grade: _____

Type of Osteogenesis Imperfacta (OI): ☐ Mild ☐ Moderate ☐ Severe

Brief history of fractures and commonly fractured bones:

Location of rodded bones:

Student's ability to recognize and respond to physical injury:

Student name _____

IDENTIFICATION CARD

☐ It is recommended to have an identification card of the student mentioning their condition, posted in the classroom. Please discuss this option with the student before checking this box. An example is included in the Appendix 1.

Additional comments:

EMERGENCY CONTACT INFORMATION

	Name	Relationship	Preferred phone #	Alternate phone #
1st				
2nd				
3rd				

FRACTURE RESPONSE PLAN

In case of an actual or suspected bone fracture

- Consult with the student first. They know their body best.
- Allow the student to communicate their needs to the personnel.

Call 911/Emergency Medical Services if:

- Open fracture or fracture with deformity
- Loss of consciousness
- Disorientation
- Very severe pain
- Suspected fracture to the spine. Warning signs include:
  - Back or neck pain
  - Decreased sensation in hands and feet
  - Decreased movement of limbs
- Unable to reach the emergency contact(s)

Actions to take until Emergency Medical Services arrive:

- Do not move the student. If the student is in an unsafe environment, move them slowly and carefully, being careful to support the injured limb and moving it as little as possible.
- Ensure the student is comfortable and in a safe environment.
- Have an adult stay with the student.
- Do not give them any food or drink because may interfere with anesthesia if the student requires surgery.
- Comfort other students and adults. They may be upset over the student`s injury. The situation will be much easier if everyone remains calm and avoids panic.
- Once the Emergency Medical Services has arrived, it may be pertinent to call the Osteogenesis Imperfecta Foundation (1-800-981-2663) or _____(specify) in order to explain this rare condition to others if the parents do not arrive soon enough.

Name of preferred hospital emergency room:

Phone number of preferred emergency room:

Address of preferred hospital emergency room:

Call the emergency contact on page 5

☐ This student has an OI Support Kit at school. (See Appendix 2 for a list of suggested items)

☐ The OI Support Kit is located:

Student name _____

Staff members trained to perform immobilizations are:

The student has medication that can be given in case of a fracture.

Medication: _____

Dose: _____

Location: _____

MOBILITY AND ENVIRONMENTAL CONSIDERATIONS

The table below describes the mobility of the student in usual circumstances. The student's condition may change due to the presence of pain, fatigue, or recovery from a fracture or surgery. Modifications may be needed if their level of mobility changes.

It is important to assess weather conditions, which may require additional assistance (e.g., snow, or icy surface)

Mobility / Location	Walks without walking aid	Walks with walking aid (specify: walker, cane, etc.)	Mobilizes independently with wheelchair	Uses wheelchair with adult assistance* (specify)	Uses an adapted bike	Requires adult supervision**
Classroom	☐	☐	☐	☐	☐	☐
Hallways	☐	☐	☐	☐	☐	☐
Outdoors/ school yard	☐	☐	☐	☐	☐	☐
Stairs	☐ Uses stairs independently. ☐ No adult supervision required, hand railing should be used for safety. ☐ Under adult supervision, hand railing should be used for safety. ☐ Unable to use the stairs. Requires ramp or elevator. ☐ An adaptation to the classroom may be required such as putting the student`s classroom on the main floor.					

*Assistance: The adult is to provide help with the task that the student is performing. Ask the student how they want you to help them.

**Supervision: The adult is to observe the student perform the task. Only offer help if the student asks for assistance.

☐ Student must wear braces when standing/walking. Specify:

☐ Student has a standing frame that should be used at school daily for a duration of approximately _____ minutes.

☐ Allow the student to leave and enter class a few minutes before their classmates to avoid crowded hallways and stairs.

☐ The student needs space for mobility for rehabilitative purpose (e.g. to practice an impacted skill after a fracture during lunchtime). Please designate an area for this practice.

Additional Comments:

WHEELCHAIR TRANSFERS

☐ Not applicable for student

Level of assistance / Type of transfer	Independent (specify: sliding, standing, uses footrest)	Requires assistance (specify)	Dependent Student needs specific plan from Occupational Therapist	Equipment needed (specify: transfer board, walking aid, mechanical lift, etc.)
Wheelchair ↔ chair	☐	☐	☐	☐
Wheelchair ↔ floor	☐	☐	☐	☐

Additional Comments:

Student name _____

TOILETING

Transfer to toilet

☐ Independent - able to transfer to toilet seat independently/safely

☐ Able to transfer to toilet seat with assistance. Specify:

Toileting Facilities

☐ Occupational Therapist **(OT)** assessment of toileting facilities at school is recommended. This assessment may include suggestions for:

- Installing a change table to help with toileting when the student is unable to transfer on their own.
- Using a reducer ring to help the student properly sit on the toilet.

☐ Refer to OT assessment as needed.

Personal Hygiene

☐ Completes hygiene independently.

☐ Completes hygiene with assistance. Specify:

Clothing Assistance for Toileting

☐ Independent - able to manage clothing for toileting.

☐ Able to manage clothing for toileting with assistance. Specify (e.g. help with fasteners):

Additional Comments:

PHYSICAL ACTIVITY

Physical Education Classes

Physical activity is strongly encouraged, as it strengthens muscles and bones in individuals with OI. However, certain precautions must be considered to ensure optimal safety of this student. Important guidelines include:

Recommendations for Inclusion:

- Participation in most non-contact sport is encouraged (e.g. badminton, archery, or tennis). Special considerations may be needed for contact sports.
- As much as possible, activities should be modified such that the student is able to participate with their entire class. In case this is not possible, the class may be split up in small groups permitting the student to participate in a similar activity with a smaller group of students. If the activity involve many students (e.g. soccer, volleyball, or basketball), the student may:
  - perform the same activity with a small group; or
  - practice the skills associated with the activity (e.g kicking a ball, dribbling and passing a ball, or shooting baskets). This would reduce the risk of falling or bumping into other students while participating in the activities.
- If the student is unable to perform an action, encourage them to suggest an alternative. In addition, the student's parents may be consulted for suggestions.
- Skills acquired from all sports should be learnt and student can help with refereeing or scoring during contact activities. Never allow the student to sit alone on the sideline.
- Generalized pain and fatigue are common in individuals with OI. Allow the student to rest if tired or experiencing aches or pains. The student knows their body best. Please listen to the student to help avoid an injury; however, the student should also be encouraged to participate in the group activity as much as physically possible.
- Swimming and playing in the water are ideal activities for the student. The water allows independent movement with little risk of fracture or injury. Please encourage the use of the pool at school when possible.
- For younger students, an imposition of a break, time out or a calmer activity would be recommended until the physical educator is familiar with the student
- Keep track of potential considerations (Appendix 3)

Adaptations Suggested

- Offer supervision if the student is at risk of falling during an activity (e.g. use of monkey bars or gym equipment)
- Promote cardiovascular activities such as running, skipping or jogging, and the use of stationary bike or rowing machine.
- Use lightweight equipment (e.g. use of foam balls, light dumbbells and beanbags)
- Wear and tie properly fitted shoes

- ☐ Offer 1 on 1 supervision
- ☐ Use an adapted bike
- ☐ Use student's sports wheelchair and/or outdoor adapted equipment
- ☐ Encourage time out of wheelchair when possible, such as using a walker
- ☐ The muscles that cross the hip joint can become short and stiff when sitting for long periods of time, especially for those students in wheelchairs.
- ☐ Promote floor stretching or yoga.

Things to Avoid

- Trampolines
- Physical education equipment scattered on the floor
- Repetitive high intensity activities (e.g. sprinting amongst groups and jumping from heights)
- Sit-ups due to risk of vertebral compression fractures
- Crowds or risk of bumping into other people or things

Physical Education Clothing

☐ Independent – able to manage clothing (e.g., t-shirt, sweatpants or shorts, running shoes)
☐ Installation of a floor mat for the student to stand on while changing
☐ Able to manage physical education clothing with assistance. Please specify:

Physical Education Exemptions

☐ If the student cannot temporarily participate in physical education class, the student could perform their physiotherapy program instead (please refer to the student's physiotherapist).
☐ In the rare circumstances that the student is exempt from physical education classes, please include the signed documents from the primary care physician.

Playtime Considerations (e.g. Lunchtime, Recess, Extracurricular Activities and After School Care)

- Keep same schedule as their peers

☐ 1 on 1 supervision
☐ Use of non-crowded playground equipment under supervision
☐ Consider alternatives if the playground is unsafe due to weather conditions (e.g. icy, or slippery), or has a fracture.
☐ Enjoy outdoor fresh air on a clean ground surface, or sitting on a bench
☐ If in a wheelchair, alternate to a sleigh to enjoy the snow
☐ Remain indoors
  ☐ Play in the gym with one or two friends under adult supervision
  ☐ Practice their rehabilitation program
☐ For students with wheelchairs, promote stretching in a designated place (e.g., infirmary or classroom).
☐ Keep track of potential considerations (Appendix 4)

Outdoor | Winter Clothing

☐ Independent – able to manage clothing (e.g. put on winter jackets, snow pants, boots)
☐ Able to manage outdoor clothing with assistance. Specify (e.g. help with fasteners):

☐ Have a small bench or chair near the locker for dressing
☐ Place shelves and hooks in the locker at an appropriate height

Additional Comments:

FIELDTRIPS

Field trips will require careful planning and possible additional accommodations. In such instances, it is important to elaborate a plan with the student, the parents, the teachers, and the healthcare professional(s). A few things to consider:

- ☐ Student to bring OI Support Kit
- ☐ Student to bring medication
- ☐ Assess availability of an adapted bathroom (if needed)
- ☐ Asses if the space is accessible (for wheelchairs, walking aids, etc.)
- ☐ Refer to the Transportation section below

Additional Comments:

TRANSPORTATION

- ☐ Use of a regular mode of transportation (e.g., public transportation, bike, walk, lift from parents/carpooling).
- ☐ Use of a car seat in preferred mode of transportation. The mode of transportation must be equipped with anchorage for the car seat.
- ☐ Use of a regular school bus.
  - ☐ Recommend student sits at the front rather than the back where the ride is more bouncy
  - ☐ Requires supervision to get on and off bus
  - ☐ Recommends attaching the transportation sticker on the window of the school bus (Appendix 5)
- ☐ The student is registered with public adapted transport or adapted transport provided by school system. Specify:

- ☐ Transportation accommodations may involve a wheelchair-accessible school bus or van.
  - The driver must be trained to use tie-downs.
  - Power wheelchairs may be heavier. Make sure the lift on the bus is able to lift the wheelchair.

Additional Comments:

Student name _____

SCHOOL EVACUATION PLAN

During fire drills and emergency evacuations, it is important to ensure the student's safety. Due to possible mobility issues and risk of falls, a plan should be put in place.

- Contact local fire department to elaborate an evacuation plan for the student.
- OT or school nurse should review the emergency plan of the school to tailor to the needs of the student.

☐ Assign an adult for supervision of the student.

Name: _____

☐ Assign two trained adults if the child is in a wheelchair, to lift him in the wheelchair down the stairs.

Names: _____

If the wheelchair is too heavy for two trained adults to lift, it is best to lift the student without the wheelchair.

Additional Comments:

SEATING CONSIDERATIONS

☐ The student should have preferential seating in the classroom (e.g., closer to the door, closer to the teacher, etc.) Specify:

☐ Ask the student where they would prefer sitting if they have hearing difficulties

☐ Consider having enough space for the student to get to their desk

☐ Consider an appropriate height for the desk and chair

SCHOLARLY CONSIDERATIONS

☐ Student needs accommodations for test taking (e.g., oral exams, use of computer, longer time to complete exam, breaks etc.) Specify:

☐ Student presents with decreased writing endurance and hyperlaxity. They may need to use a computer or modifications, please contact treating OT for more information.

☐ Student may need more time to complete class work, assignments, or homework.

☐ If the student cannot temporarily attend school in person due to a fracture or recent surgery, remote learning should be considered.

☐ Student should have an extra set of books at home and in the classroom to avoid having to carry them around.

Additional Comments:

ASSENT AND CONSENT

Consent to release information: I authorize and provide consent to the school staff to use and/or share information in this plan for purposes related to the education, health and safety of me/my child. This may include:

☐ Displaying my/my child's photograph on paper notices or electronic format(s) so that staff, volunteers, and school visitors will be aware of my/my child's medical condition.

☐ Communicating with bus operators.

☐ Sharing information in special circumstances to protect my/my child's health and safety.

■ Yes ☐ No

Consent to transfer to hospital: I consent and authorize the transportation of me/my child to a hospital, if required, based on the judgment of school staff. I also permit a staff member to accompany me/my child during transport.

Please note: the school principal or designated staff shall decide if an ambulance is to be called.

☐ Yes ☐ No

Consent to the plan: I am aware that school staff are not medical professionals and perform all aspects of the plan in good faith and to the best of their abilities:

☐ Yes ☐ No

Student name _____

AUTHORIZATION

Parent/guardian signature: _____ Date: _____

Parent/guardian name: _____ Relationship: _____

Student signature: _____ Date: _____

Heath care professional (HCP) signature: _____ Date: _____

HCP name: _____ Role: _____

Principal signature: _____ Date: _____

Principal name: _____

ANNUAL RENEWAL

When requirements change significantly, complete a new Individualized Care Plan with all involved.

If there are no changes between school years, use this sign-off sheet to confirm the plan has been reviewed by the school, the parent(s), and, when age-appropriate, the student.

This plan remains in effect for the _____ to _____ school year without change.

Parent/guardian signature: _____ Date: _____

Principal signature: _____ Date: _____

Student signature: _____ Date: _____

This plan remains in effect for the _____ to _____ school year without change.

Parent/guardian signature: _____ Date: _____

Principal signature: _____ Date: _____

Student signature: _____ Date: _____

This plan remains in effect for the _____ to _____ school year without change.

Parent/guardian signature: _____ Date: _____

Principal signature: _____ Date: _____

Student signature: _____ Date: _____

This plan remains in effect for the _____ to _____ school year without change.

Parent/guardian signature: _____ Date: _____

Principal signature: _____ Date: _____

Student signature: _____ Date: _____

This plan remains in effect for the _____ to _____ school year without change.

Parent/guardian signature: _____ Date: _____

Principal signature: _____ Date: _____

Student signature: _____ Date: _____

APPENDICES

Appendix 1: Identification and Passport

Example of student identification card that gives instant access to the student's medical condition.

Identification card

Photo	Name _____ Class _____	This student has brittle bone disease. Their bones are fragile. **Please handle with care.** For any concerns, refer to a member of the staff who is aware of this student's condition.

Passport

You may also create a passport at the following website: https://wapps.sickkids.ca/myhealthpassport/

Appendix 2. List of Suggested Items to be Included an OI Support Kit

Description of contents contained in the OI Support Kit created for children with Osteogenesis Imperfecta following a fracture and requiring immobilization

Item	Description and Rationale
1. Instructional Card # 1	Presentation card: brief rationale of the project and links to the videos
2. Instructional Card # 2	Illustration of the main immobilization for upper extremities fracture (recto-verso: arm and forearm)
3. Instructional Card # 3	Illustration of the main immobilization for lower extremities fracture (recto-verso, upper and lower leg)
4. ACE Bandage with Self Closure 3in	An elastic bandage that may be wrapped around an injured area to control swelling or around a cast to secure it in place.
5. ACE Bandage with Self Closure 4in	An elastic bandage that may be wrapped around an injured area to control swelling or around a cast to secure it in place.
6. 3M Coban Cohesive Bandage 3in	A self-adherent elastic tape that may be wrapped around an injured area to control swelling or around a cast to secure it in place.
7. 3M Coban Cohesive Bandage 4in	A self-adherent elastic tape that may be wrapped around an injured area to control swelling or around a cast to secure it in place.
8. Padding Cast 7.5cm	Cotton bandage that may be wrapped around an injured area to provide padding and prevent friction
9. Padding Cast 10cm	Cotton bandage that may be wrapped around an injured area to provide padding and prevent friction
10. One-Step Splint 3x35in	A splint made of two layers of padding covering a fiberglass slab for an easy one step immobilization.
11. Scissors 5.5 inch	To help cut cast
12. Stockinette	First, thin layer of fabric that is applied directly on the skin when casting, preventing movement of the cotton padding and friction from cast edge.
13. Human Bone Stress Ball	Help relieve stress and muscle tension. May be used as a distraction tool.
14. Drawstring bag	Bag to carry all the tools needed to immobilize a fracture.
15. Sam Splint 5.5 x 36in	Splint made of soft aluminium with a foam coating that is applied to an injured area to stabilize a fracture.
16. Video #9	Trousse de premiers soins OI - Immobilisation de la cheville *ou du pied:* https://vimeo.com/273559934
17. Video #10	*Trousse de premiers soins OI - Immobilisation du bras* : https://vimeo.com/273558129
18. Video #11	*Trousse de premiers soins OI - Immobilisation de l'avant bras* : https://vimeo.com/showcase/5149282
19. Video #12	*OI Support Kit-Immobilization of the Forearm:* https://vimeo.com/showcase/5149282
20. Video #13	*OI Support Kit-Immobilization of the Femur:* https://vimeo.com/showcase/5149282
21. Video #14	*OI Support Kit-Immobilization of the Arm:* https://vimeo.com/showcase/5149282
22. Bones and Fractures Memory Game	Help children learn about their bones, fractures and different therapies used in OI. Offer a potential distraction tool.

Student name _____

Appendix 3. List of Adapted Activities for Physical Education

Please use the table below to suggest ideas for adapting activities for this tstudents with OI. This table can be modified and re-visited yearly by physical education teachers to foster inclusion in gym classes.

Original activity	Adaptation
e.g. Balance Beam	Walking on a line rather than a balance beam to practice balance
e.g. Archery	Use a slingshot as a substitute for the crossbow

Appendix 4. List of Adapted Activities for Lunchtime, Recess, Extracurricular Activities and After School Care

Please use the table below to suggest ideas for adapting activities for this students with OI. This table can be modified and re-visited yearly by teachers, animators and supervisors to foster inclusion in the school setting

Original activity	Adaptation
e.g. Tag	Crawling instead of running

Appendix 5. Transportation Sign to be Posted On School Bus and Other Vehicles