

iManage my OI

Argerie Tsimicalis RN PhD



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A Participatory Approach for the Development of a Self- Management and Transitional Care Program for Adolescents with Osteogenesis Imperfecta

Argerie Tsimicalis RN PhD

Assistant Professor, McGill University

Nurse Scientist, Shriners Hospitals for Children-
Canada



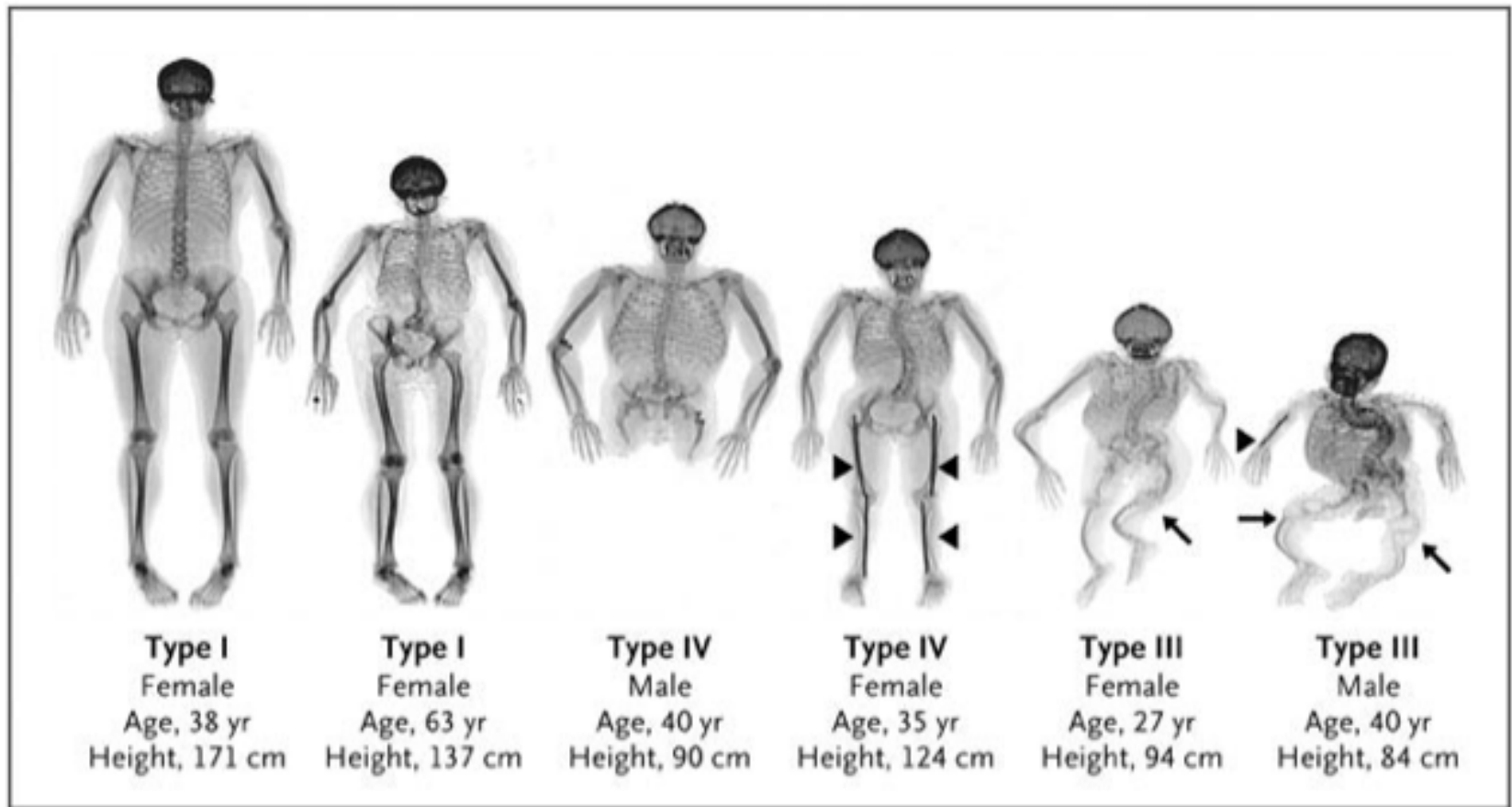
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Samantha

Osteogenesis Imperfecta (OI)

1:10,000



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Paucity of Research (n = 4883)

PubMed

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Search results
Items: 1 to 20 of 4883

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☐ 1. [Osteoblastic differentiation of bone marrow mesenchymal stromal cells in Bruck Syndrome.](#)
Kaneto CM, Lima PS, Zanette DL, Oliveira TY, de Assis Pereira F, Lorenzi JC, Dos Santos JL, Prata KL, Neto JM, de Paula FJ, Silva WA Jr.
BMC Med Genet. 2016 May 4;17(1):38. doi: 10.1186/s12881-016-0301-7.
PMID: 27146342 **Free PMC Article**
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☐ 2. [Eight mutations including 5 novel ones in the COL1A1 gene in Czech patients with osteogenesis imperfecta.](#)
Hruskova L, Fijalkowski I, Van Hul W, Marik I, Mortier G, Martasek P, Mazura I.
Biomed Pap Med Fac Univ Palacky Olomouc Czech Repub. 2016 Apr 27. doi: 10.5507/bp.2016.022.
[Epub ahead of print]
PMID: 27132807

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Try the new Display Settings option - **Sort by Relevance**

Results by year

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Related searches
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OI and Nursing (n = 63)

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Search	Add to builder	Query	Items found	Time
#3	Add	Search (#1 and #2)	63	10:30:49
#2	Add	Search nursing	634884	10:30:24
#1	Add	Search osteogenesis imperfecta	4883	10:24:42



~472 OI patients from Canada, USA and other 60 Countries



- Largest cohort of patients in North America
- Internationally acclaimed for establishing the worldwide standard of care, pioneering the treatment, and testing its effectiveness



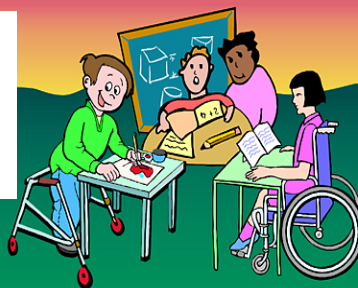
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PROGRAMME DE TRANSITION: Un voyage vers l'indépendance.

TRANSITION PROGRAM: A Trip to Independence.



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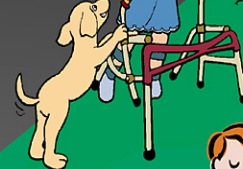
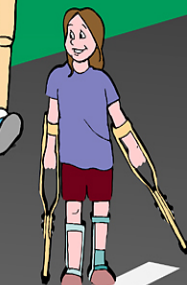


École-Amis-Activités:

- Participer aux activités en milieu scolaire, en famille et au sein de la communauté.

School-Friends-Fun:

- Going to class and participating with family & friends in the community.



Pour commencer:

- Développer des habiletés pour les soins personnels, se vêtir, faire sa toilette et se déplacer de façon autonome.

Getting Started:

- Learning how to manage personal care tasks, dressing, grooming, & moving about on your own.



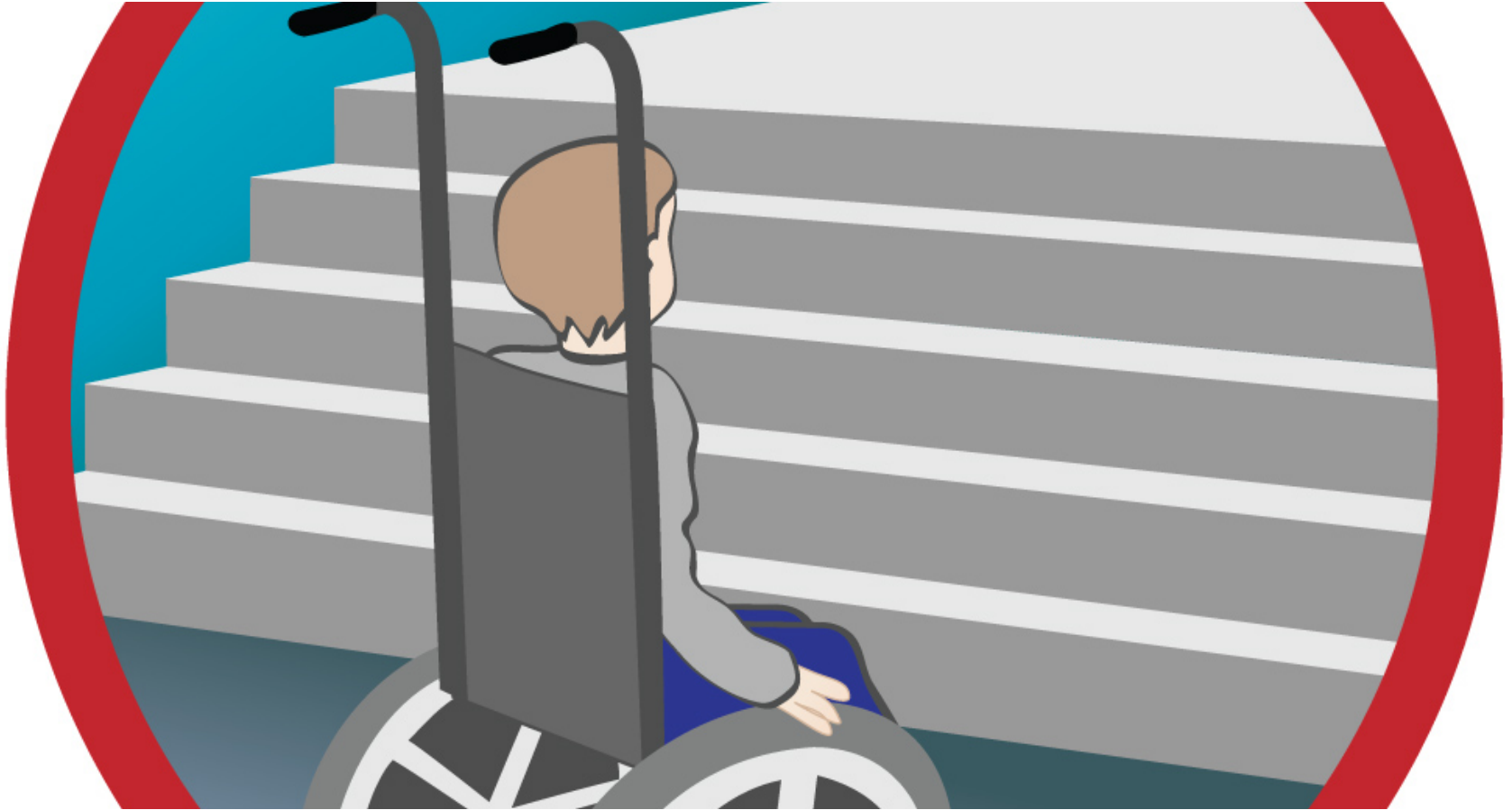
Une vie saine:

- Développer un intérêt pour les sports, la nutrition, les passe-temps et les relations interpersonnelles.
- Organiser les activités de la vie quotidienne et le transport.

Healthy Life Skills:

- Developing interest in sports, nutrition, hobbies and relationships.
- Organizing transportation and domestic needs.

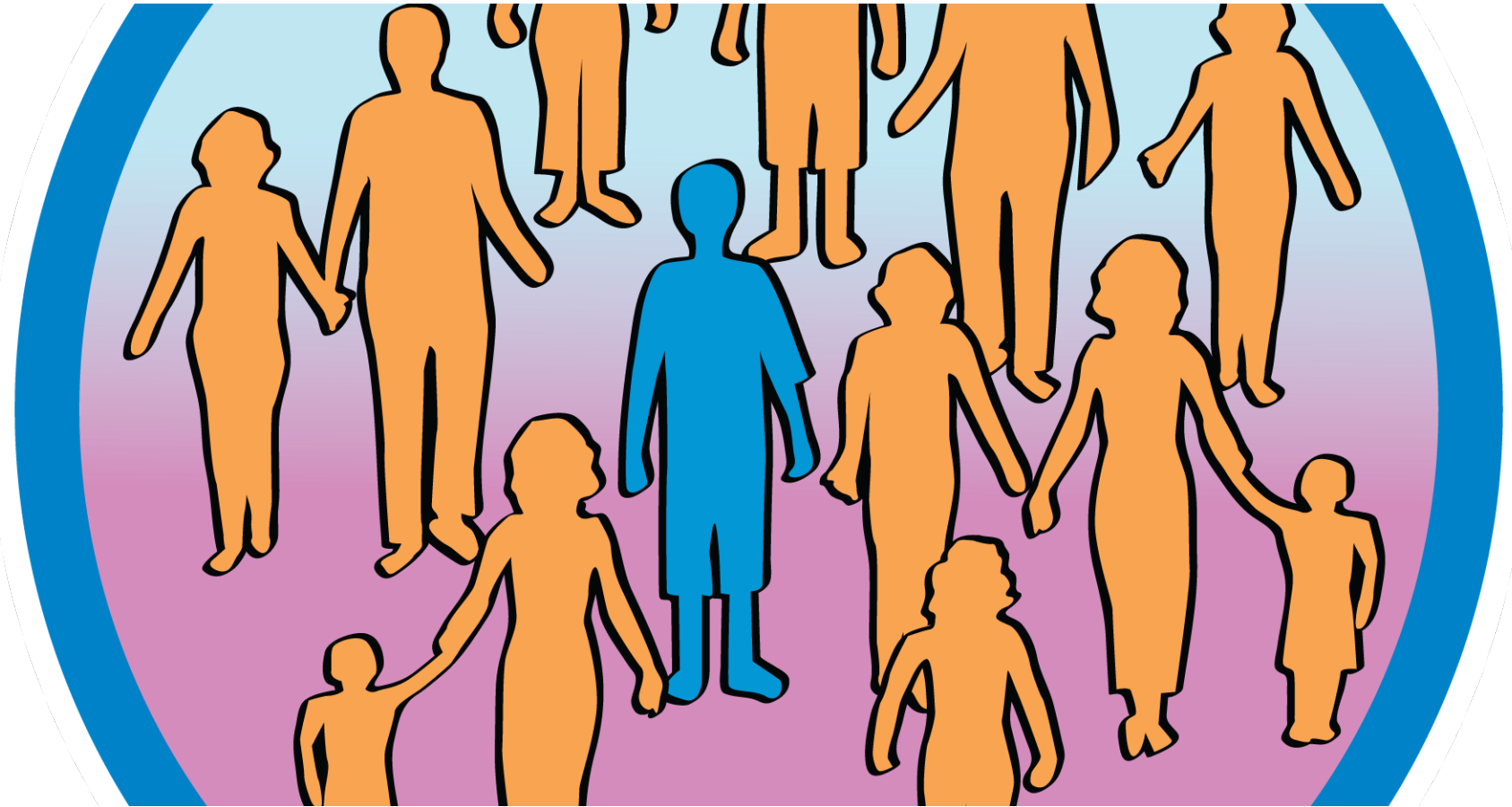
Dropped in the Jungle with No One to Call



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NUR2 612 Project: Alisha Michalovic and Charlotte
Anderson (to be submitted for publication)

They Don't Know How to Treat Me!

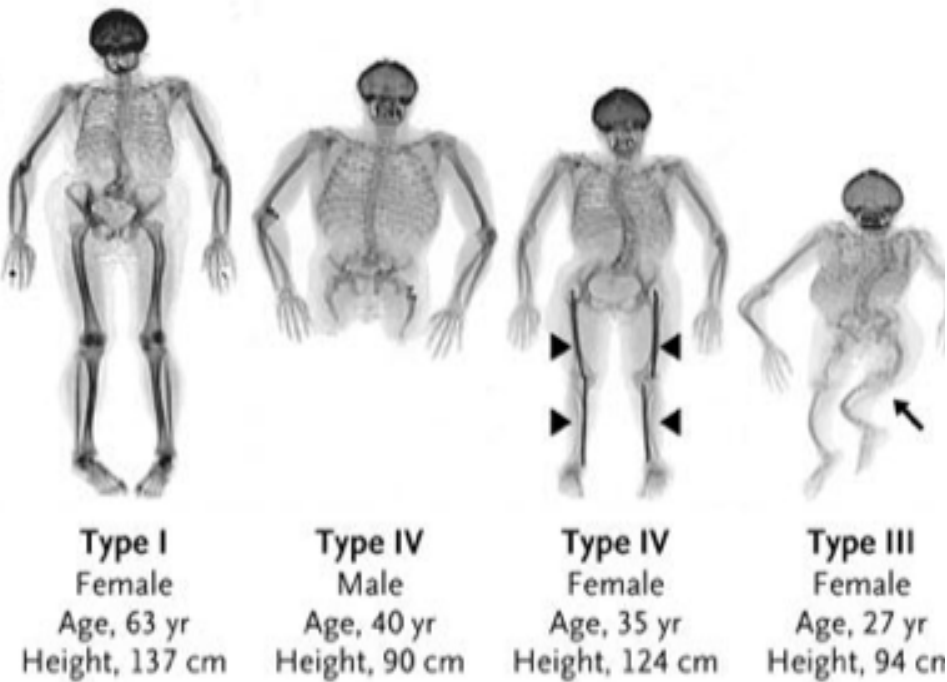


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Anderson (to be submitted for publication)

**“il m’a dit, « tes os ont l’air
bizarre, je ne sais pas quoi
faire avec toi. » ... [Le docteur
est] supposé m’aider mais [il]
ne [sait] pas quoi faire!”**

OI Nursing



One of our OI patient ambassadors

Our Research Team

Sharon Brissette
*Director of Nursing and
Patient Care Services*
sbrissette@shrinenet.org



**Kelly Thorstad, MSc(A)N,
PHCNP**
*Clinical Nurse Specialist/
Nurse Practitioner*
kthorstad@shrinenet.org



Argerie Tsimicalis, RN PhD
*Nurse Scientist, Assistant Professor,
Ingram School of Nursing, Faculty
of Medicine, McGill University*
argerie.tsimicalis@mcgill.ca



Claudette Bilodeau, RN B.Sc.N.
Research Nurse
cbilodeau@shrinenet.org



Khadidja Chougui, B.A.
Research Assistant
Expert former patient
khadidja.chougui@mail.mcgill.ca



Fostering Collaborations



Claudette Bilodeau RN BScN

(23 years at Shriners)

« Ma connaissance du milieu et ma position au sein de l'équipe de recherche me permettent de faire connaître la recherche infirmière, de l'expliquer dans un langage que je souhaite signifiant pour mes collègues directement impliqués avec leurs patients. Leurs craintes et leurs frustrations me sont familières puisque je les ai expérimentées pendant plusieurs années. »



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Taking Charge

Managing JIA Online

Français

Ask an Expert

Parents

Home

Introduction

1. About JIA

2. Understanding Diagnosis

3. Managing Your Symptoms

4. Managing Stress

5. Relaxation

6. JIA Medications

7. Distraction

8. Other Types of Care

9. Managing Your Thoughts

10. Therapies, Self-monitoring, and Supports

11. Your Lifestyle

12. Looking Ahead

Journal

Forum

GLOSSARY

A B C D E F G H I J K L
M N O P Q R S T U V W
X Y Z

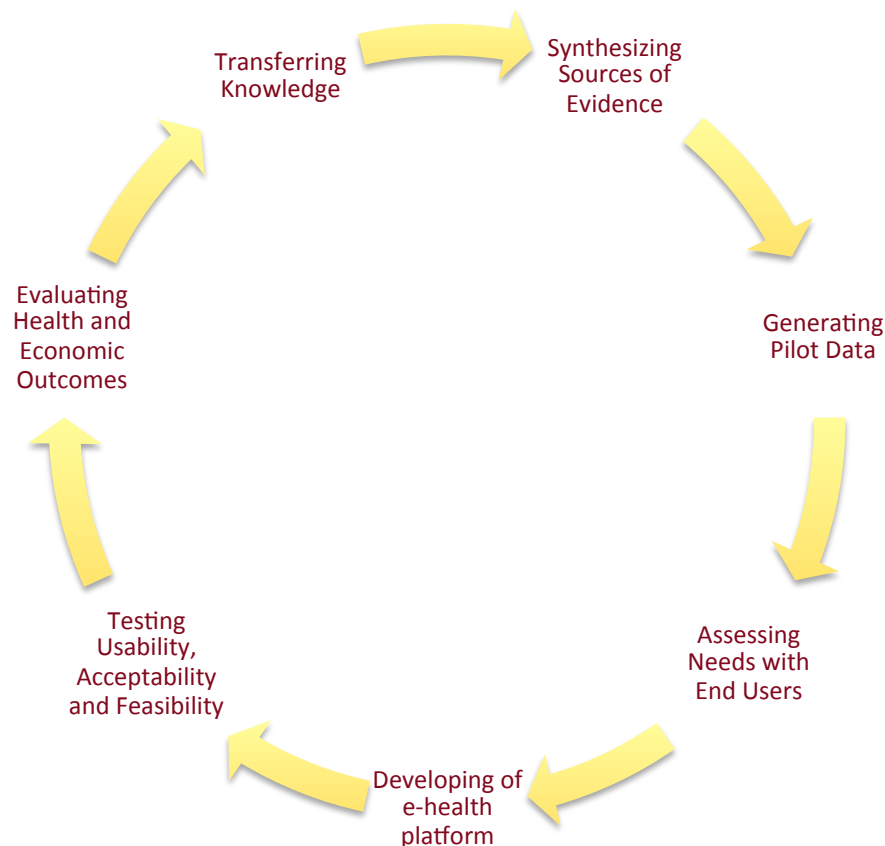
Taking Charge: Managing JIA Online

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Created by Jennifer Stinson, PhD, RN-EC, CPNP
Mary Jo Haddad Nursing Chair in Child Health and
Senior Scientist

Teens Taking Charge: Managing OI Online

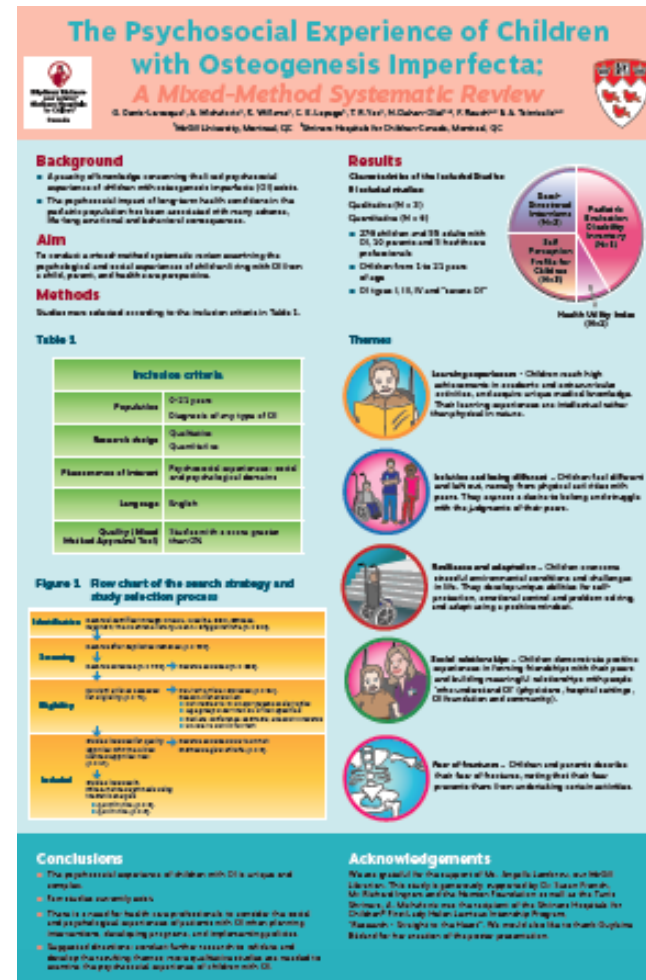


A multi-phase, sequential approach for developing, testing, evaluating and translating Teens OI



Synthesizing Research Evidence

- Published
 - Quality of Life
 - Psychosocial Experiences
- Submitted
 - Pain
- In Progress
 - Parenting Experiences
 - Long Term Effects



Synthesizing Social Media Evidence



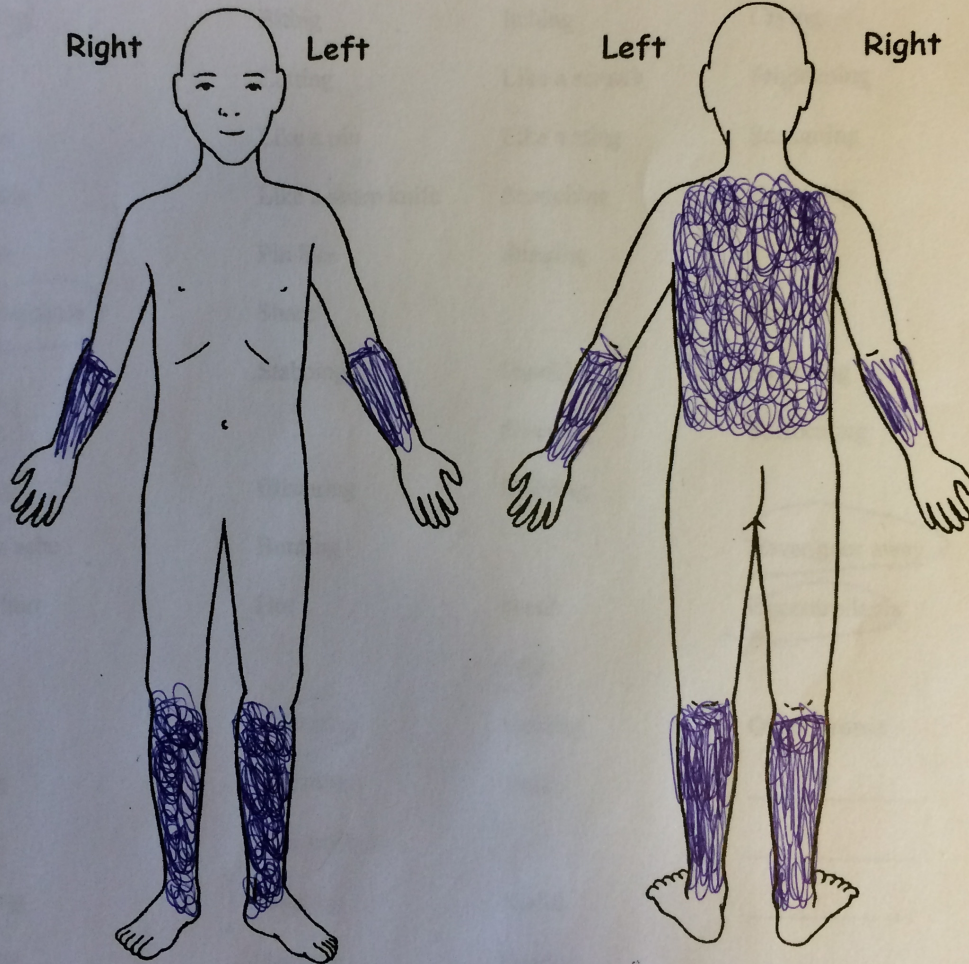
Me, Myself and O.I.

[34 = number of fractures]



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MAKE THE MARKS AS BIG OR SMALL AS THE PLACE WHERE THE PAIN IS.



Generating Pilot Data

- To inform components of the Teens OI modules
- To provide estimates for sample size calculations and outcome measures

Assessing Needs with End Users

- Mixed Methods Design
- n = 15-20 parent/adolescent dyads or triads (with siblings, if appropriate)
- Data Collection
 - Transition Readiness Instrument
 - Interviews
 - Eco-maps and Genograms
 - Photovoice

Protocol to be submitted for
ethical approval



Developing Teens OI with End Users

- Adapt Modules and Content
- Translate Sources of Evidence into Formats Appealing to OI population
- Imbed Clinician and Patient Expertise
- Create Music, Video, Vignettes, Graphics, Tests, Quizzes
- Offer Program in English and French
- Test, Evaluate, Translate...



Our Donors

**Mr. Richard Ingram,
Dr. Susan French and the
Newton Foundation**



Merci RRISIQ!

