# Facts about Osteogenesis Imperfecta

## Transition from Pediatric to Adult Care

Transition in terms of health care is an organized and planned effort to assist adolescents and young adults to move from the pediatric system into the adult-based system. Many formal transition programs also include components that cover education/vocational options, independent living skills, as well as dating and relationships. Pediatricians and others who are involved in pediatric care have important roles to play in the transition process. The traditional transition age is 18-21 years but planning and preparation should begin much sooner.

**The following is a list of goals for the physician caring for a young adult with OI:**

- Maintain current health status.
- Preserve or improve level of function.
- Assure continuity of medical and surgical care.
- Provide psychosocial support with referral to counseling and other services if needed.

The incidence of fractures tends to decrease once the young person with OI is through puberty, but OI is a systemic connective tissue disorder. Problems other than fractures, including ligaments, tendons, muscles, peripheral joints, the eye and cardiovascular system may increase. Childhood respiratory problems such as asthma usually persist. There continues to be a need for regular check-ups to monitor general health, hearing, weight management, and reproductive health.

The young adult must become adept at managing their general health, understanding their special medical and psychosocial needs and establishing their own interdisciplinary health care team. For the young person who has OI the following transition topics are especially important.

- Taking responsibility for one's own health care.
- Being knowledgeable about OI in general and how it changes after puberty.
- Knowing their personal health history.
- Being able to communicate confidently with physicians.
- Understand how their health insurance works.
- Having identified adult care resources who are informed about OI including:
    - Primary care physician (PCP) who may be an internist or a family physician. The PCP is the most important part of the adult's health team and becomes the manager and person to go-to when a referral to a specialist is needed.
    - Musculoskeletal team: orthopedist, physiatrist or physical therapist.
    - Specialists in pulmonology, cardiology, audiology or neurology depending on their personal and family health history.
    - For women – gynecology

**Resources for Physicians and Patients**

**The Got Transition Center for Health Care Transition** is a cooperative project between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. The website www.gottransition.org is a clearinghouse of materials for physicians, young adults and families.

**Resources continued:**

**Video Serious** from Nemours Children's Health System. Titles include:

- Becoming an Adult: Taking More Responsibility for My Care
- Becoming an Adult: Legal and Financial Options
- Becoming an Adult with a Genetic Condition
- Becoming an Adults: Family Planning and Genetics

The videos can be viewed at: http://www.nemours.org/service/medical/transitionofcare.html

**References**

Dogba MJ, Rauch F, Wong T, Ruck J, Glorieux FH, Bedos C. From Pediatric to Adult Care: Strategic Evaluation of a Transition Program for Patients with Osteogenesis Imperfecta, BMC Health Services, Research 2014, 14:489.

Shapiro J, Germain-Lee E. Effecting the Transition from Adolescent to Adult Medical Care. Journal of Musculoskeletal Neuronal Interactions, 2012, 12:24-27.

**Thank you to Cory Nouri, MSS MLSP Patient Transition Social Work Coordinator Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE, for assisting with this document. October 2015**