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Human Rights and Disability

Human Rights, 30482, cl.31

Presented By Vittoria Montinari





F.O.P. Italy

Associazione Italiana Fibrodisplasia Ossificante Progressiva





What is it?

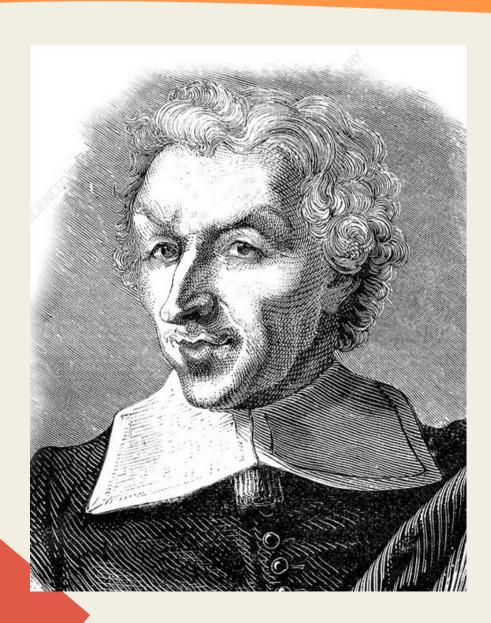


- Genetic condition
- Heterotopic ossification:
 the body generates extra bones in places where
 there shouldn't have been any.
- Articulations and extraskeleton: rigidity and permanent immobility
- Disease's explosion: first20 years of life

- Diagnosis: rare and very hard
- Progression: uncertain



Historical Development



- First case: reported in 1692 by Dr. Guy Patin in France
- 3300 cases around the world recorded until now
- At the moment: 700 cases in the world
- 1 person affected over 2 mln
- 35 cases in Italy

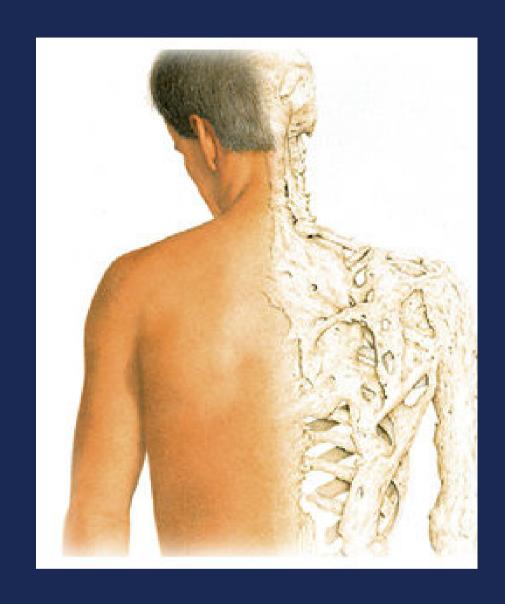
Main reasearch center: University of Pennsylvania School of Medicine



What should be avoided

- Falling down
- Physical Activity
- Surgery: if not strictly necessary, additional issue of infections

- Fear
- Pain
- Flareup







International Fibrodysplasia Ossificans Progressiva Association

- Non-profit organization
- Born in 1988
- Transnational network to overcome isolation
- Advocate, education, and support

GOALS:

- Global awareness
- Funds for Cure's Research





National Law

Affected People's Rights

- 100% inability declaration
- Exemption from some health expenditures
- Disability Pension since 18 years old
- Specific aid for comfortable life

DPCM 12.01.2017:
FOP exemption
code



Essential assistance's request

Law n. 104/92





National Law

Constitutional Articles

- Art.4: involved in the workforce
- Art 34: involved in school
- Art. 32: Right to healthcare

Focus.

Art 38:
Right for
disabled people
to leave with all
means needed
and receive
social
assistance

Framework

Article 2 and 3: equality, dignity and invioable rights





European Union's Law

<u>Charter of Fundamental Rights of the</u> <u>European Union</u>

- Signed in 2000 in Nice, updated in 2007 in Strasburg
- Legally binding with Treaty of Lisbon
- Civil, political, and socioeconomic rights of EU citizens

Focus.

Art. 26: Involvement for people with disabilities:
Autonomy,
Professional and Social inclusiveness

Basis into Art.15: equal involvement in labor force





International Law

UN Convention on the Rights of Persons with Disabilities

- Signed in 2007 in New York, effective from 2008
- Goal: Social development
- Equal human rights and dignity
- 2022: Ratified by 185 countries

Effects.

- "Right to have rights"
- Physical and Mental disability
- Promotion of human rights





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Thank you!