

UNITI - General information

What are we?

UNITI is the first and only association in Italy to be created with the purpose gathering and helping persons affected by any kind of disease having Ichthyosis as main or secondary symptom.

What is Ichthyosis?

Ichthyoses are a group of Genodermatoses - genetic disease related to skin - whose common factor is the appearance of skin as "scaly", dry, fissured, eritemic, blistered or exceptionally thick. Scales can be nearly invisible or obvious even to casual observation and other symptoms can be from nearly non-existent to imposing and even, in some types, non-compatible with life. Recently a reclassification of these affections redefined them as Disorders Of Cornification (DOCs). The disorder is generally evident since birth or shortly after and almost always within a year of life. There is no cure at this time but local and systemic treatment can improve the condition of the patients, especially in the most difficult cases.

Ichthyoses are in fact very different in appearance, gravity and diffusion but, when not minimal, have a big impact in the social, emotional and personal life of the carriers. Simply speaking in an ichthyotic skin the production of new skin is either too fast or lacking some of the components necessary to allow dead skin cells to be normally released, resulting in an abnormal accumulation of skin layers. This situation can produce a series of problems depending on the type and importance of the disorder.

There are five kinds of disorders generally referred to as "Ichthyosis" but at least twenty more diseases, syndromes and conditions have ichthyosis as a symptom. Many of these are complex disorders, expression of extended mutations involving, among the others, also genes responsible for the correct skin growth.

Ichthyoses are, excepted for the Vulgaris type, rare or extremely rare disorders. Here is reported a table displaying some data. The incidence figures are either taken from epidemiologic studies or, for the most rare types, best-guessed by expert specialists or researchers, mostly from the USA. The frequency is based on a 60 million people model. Our experience shows that in Italy Lamellar I. is probably much more frequent than either Epidermolytic Hyperkeratosis or Congenital Ichthyosiform Erythroderma but these figures are certainly not conclusive or backed up by extensive epidemiologic studies.

Type	Incidence	Frequency in Italy	Inheritance
I. Vulgaris	1: 300	200.000	AD
X-linked I.	1: 2000-3000	20.000-30.000	XR
Epidermolytic Hyperkeratosis	1: 100.000	600	AD
Congenital Ichthyosiform Erythroderma	1: 100.000	600	AR
Lamellar I.	1: 200.000	300	AR-AD
Other forms, syndromes, diseases (about 20)	Less than 1: 500.000	1200?	AR

A few words on our "history"

The first three people starting the story met in year 2000. All of them believed Ichthyosis was so rare a disorder they'd never find anybody else with it.

The fast development of internet access and the e-mail gave them access to a much wider public and, taking advantage of a willing association (the ASNVP, defending the cause of people affected by Psoriasis and Vitiligo, in Milan) they

formed a special interest group focusing on Ichthyosis the "Gruppo Ittiosi", with an independent internet site and an internal mailing list. Contacts were established with fellow associations both in Europe and the USA.



Unione Italiana Ittiosi

Viale Vasco de Gama, 72 - 00121 ROMA RM, Italia - info@ittiosi.it - <http://www.ittiosi.it> - tel. +39.06.5611563, +39.328.1138939

By the middle of year 2001 they had grown to about 60 people and had their first convention in a leading medical institution specialized in Dermatology, the IDI - Istituto Dermopatico dell'Immacolata, in Rome. Succeeding organization efforts, always based on voluntary work, developed the Group in a more structure open to self promotion and research of contacts outside the small circle of the affected people. The Group participated in the Rare Diseases Association Convention of 2002 a ISS in Rome and contacted other organisation both social and medical such as UNIAMO, Mario Negri Institute and the ISS.

The Final Goal for the Gruppo Ittiosi was to develop into an independent association specifically aimed at people with Ichthyosis. This objective was finally reached the 31st of march 2003, when UNITI was founded in Rome. At the time the dissolved Gruppo Ittiosi was counting more than a hundred members throughout Italy.

What it's all about

The purpose of UNITI is to try and bring together all the people in Italy either affected by Ichthyosis of any kind or interested in it. The patients can greatly benefit from the self-help and understanding which the association can give them as their disorder, even when not actually disfiguring, can be very hard on them. Isolation and low self esteem are common and termoregulation problems beside the "scaly skin" appearance can make even staying out of doors in less-than-mild climates rather difficult. As most people with Ichthyosis are born with it, childhood and puberty can be, from a social point of view, an unhappy experience.

UNITI aims at expanding its base by promoting itself in specific areas where contacts can be reached more easily. Research and clinical institutions, patients association and other forms initiatives regarding genetic and/or rare disorders are among the means most used to reach fellow people.

The other main field of activity is the promotion of the knowledge of Ichthyosis and support of farmacological, medical and genetic research on this disorder either directly or through specialistic or mass media.

The support in the struggle for recognition of right to state provided treatment in serious cases by application of existent but disregarded laws is also an important activity which will be accomplished also by involving national pressure group and organizations as the Tribunale per i Diritti del Malato or ADICONSUM in individual or collective legal action.

About us

UNITI is an association of volunteers with a nationwide scope. Its base is in Rome as this is the center of political activities but, as the situation demands, its members are able to cover most of the nation and thus participate in Forums or other activities. Local meeting are held throughout the year and, as the association will grow, sectorial or regional chapters will be created.

The association will be taking full advantage in the Italian laws entitling it to request ONLUS (no-profit socially useful organization) status which will give it title to acquire public support and funds.

The association is developing a partnership with IDI with the goal of offering free consultancy to its members and a solid dependable medical Partner able to boost its reputation as a serious provider of general information about Ichthyosis.