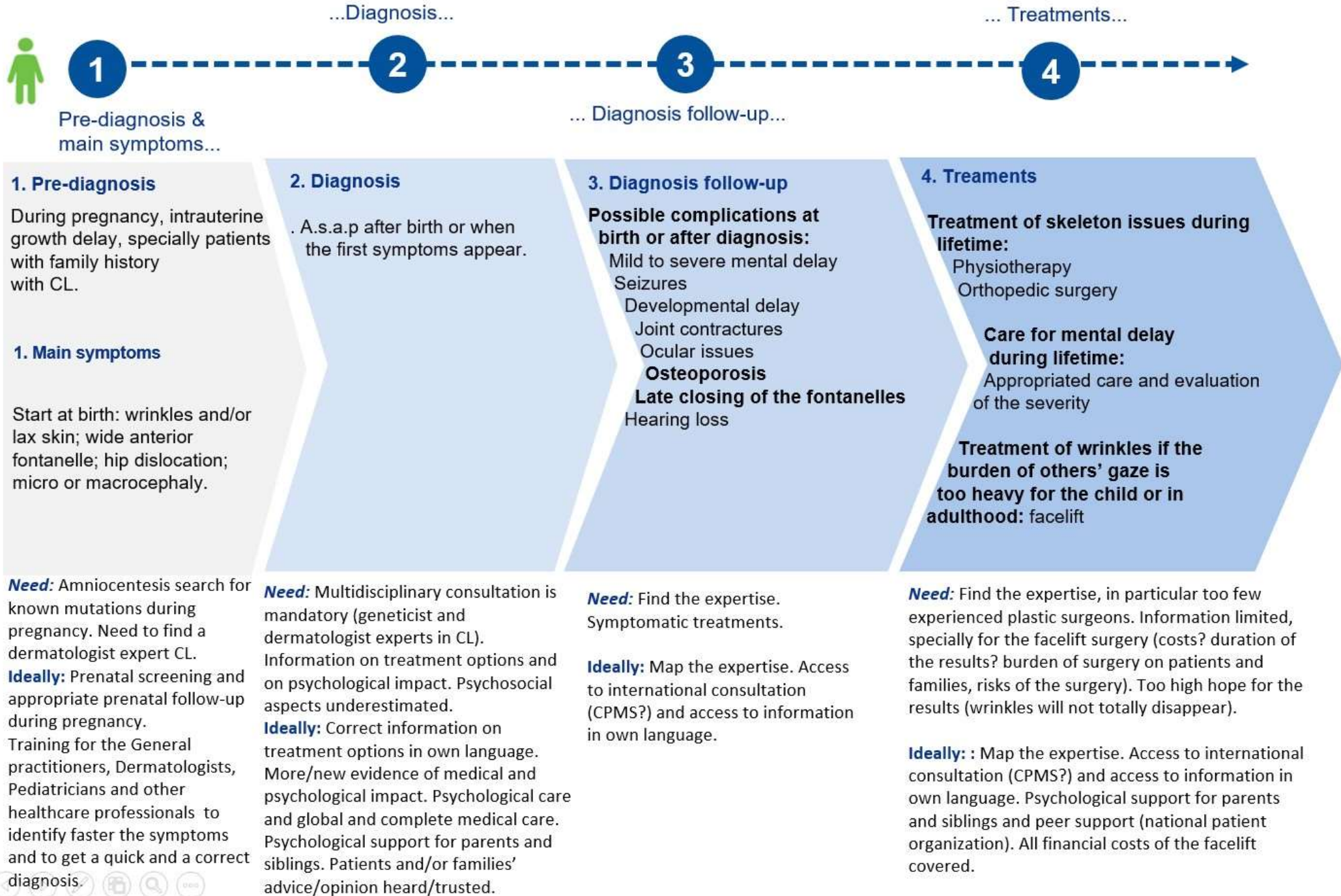


Cutis Laxa with Neuro and/or Skeleton Symptoms Patient Journey (1)



Cutis Laxa with Neuro and/or Skeleton Symptoms Patient Journey (2)

... Psychological follow-up...

...Palliative care and Memorial...



5. Family Planning

During early adulthood, gene mutation transmission in dominant or recessive form.

Need: Information on the risks during pregnancy.

Ideally: Patients received information if they want to have a child, specially on Pre Natal testing and in vitro fertilization and risks in case of pregnancy (mother and child). Consultation with an expert counselor.

6. Psychological follow-up

During lifetime due to others' gaze burden and to medical follow-up burden.

Need: No overview on types of psychological therapies (hypnose, behavioural therapy, therapy, analytical therapy, family therapy, etc.). Expert psychotherapists for Cutis Laxa (there are none as of today).

Ideally: Psychological guidance on self-acceptance, self-esteem. Easy access to the different types of psychological therapies. Psychotherapists trained and expert with the disorder.

7. Follow-up care

During lifetime, comorbidities evolution, skeleton evolution and seizures

Need: Psychosocial challenges (school, work, social life). Psychosocial burden/Quality of Life. Poor knowledge on material/resources for kids, youngsters, school, teachers, siblings, peers, sports/social activities. Moving to adult care treatment 13-16 and 18> adulthood. Skin care (sun). Daily life habits (diet, smoking, sports). Patients' social care. Support for family helpers.

Ideally: Awareness for social surrounding. Psychological support for patients, siblings and parents. Multi-disciplinary consultation. Well organized transfer to adulthood in medical field (dermatology/cardiology/pulmonology). Access to information in own language on skin care. Support for family helpers. Respite Centers with global and total care of the patient.

8. Palliative care and Memorial

Need: Guidance/support and special trained councilors in palliative care.

Ideally: Connection with medical experts and with close peer expertise for daily support. Collectively commemorate people who passed away.