



1. First symptom
 Supravalvular aortic or pulmonary stenosis,
 Low growth, characteristic Physiognomic aspect
 Hypercalcemia
 Feeding difficulties
 Dental abnormalities
 Hernias
 Hyperacusis
 Musculoskeletal problems
 High urinary frequency - nocturnal enuresis

2. Diagnosis & 1st Treatment
 Heart controls (surgery if necessary)
 Neuro - psychomotricity
 Logopaedia
 Physiotherapy
 Music therapy

3. Clinical & Mental Check
 Clinical follow up (twice yr)
 Table of growth specific for WS and guidelines about what to do at the different ages (cardiological controls, pressure, endocrinological controls, and many others)
 Neurological FU (each yr) to evaluate the stage of mental development and the gap with the normal parameters

4. Follow-Up
 Program of mental improvement, attending to a neuro-psychotherapy x2 week until 6/8 years;
 Speech therapy programme (from 2 to 4/5);
 Music therapy all lifelong;
 Educational program to improve their autonomy.

5. Social Care
 Educational support at home to develop autonomy
 Psychological support to afford anxiety and to implement awareness about "self" /who they are, which are their limits, why they can't do what other people are usually doing etc.).
 Occupational therapy
 Recreation programs

Ideally:
 A centre of competence that could bring together all the symptoms asking to a geneticist to do specific analysis.
 The capability to recognize symptoms and quickly give to parents a diagnosis.

Ideally: The chance to do all the analysis in the same place;
 Capability of communication to afford the first steps into the Syndrome;
 Start the early intervention to accelerate the development (especially motion perception and micromanipulation).

Note: Case Manager / Coordinator and Multi-Professional Approach!
Ideally:
 All the therapy needed to express at the best all the potentiality of the person

Note:
 Coordination Centre to case manage a multi-professional team (teacher, therapists, doctors, family, educators....)
 See MDT x twice yearly
 Aim to improve capability and quality of life!

Ideally:
 We need a well-structured social system that could give us a guideline about all the things needed. We should find answers to our questions and solution for our problems!