MANAGING MORQUIO A WITH MY HEALTHCARE TEAM

TOGETHER WITH YOUR GENETICIST AND HEALTHCARE TEAM, YOU CAN TAKE CHARGE OF YOUR MORQUIO A.

The more informed you are about how each member of your healthcare team can help you, the better you will be able to partner with them to manage your overall care.

The following chart has been adapted from the "International Guidelines for the Management and Treatment of Morquio A Syndrome." The chart below provides an overview of the assessment types and frequencies recommended by the Guidelines for each of your body systems.

Specialist	Assessment[a]	Frequency[a]
Geneticist/ pediatrician	Medical history	Every visit
	Endurance (6-minute walk test)	Annually
	Growth	Every visit
	Disease burden (pain assessment and reproducible, age-appropriate quality of life questionnaires eg, EQ-5D-5L)	Annually[b]
Orthopedist	Upper/lower extremities (standardized function tests, radiographs)	Annually, as clinically indicated
	Spine (spinal cord compression evaluation)	Annually, as clinically indicated
Cardiologist	Heart health (to look for abnormalities)	Annually, as clinically indicated
Pulmonologist	Respiratory function (tests to measure lung function)	Annually
Neurosurgeon	Neurological function (tests to evaluate spinal cord compression)	Every visit (minimally every 6 months)
Ophthalmologist	Vision (eye exams)	As clinically indicated
ENT	Hearing	Annually
Dentist	Dental evaluation	Annually
Physiotherapist	Physical evaluation	Annually

[a] For additional information, consult the Guidelines.
[b] Pain assessment should be conducted every 6 months.

Use the reverse side to begin developing your management plan with your geneticist. Your geneticist will help you to determine the specific tests you will need and the specialist you will be referred to in order to best manage your Morquio A.

Open communication between you and your team of doctors is the key—start the conversation by providing your doctors with a copy of "The International Guidelines for the Management and Treatment of Morquio A Syndrome."

MY PLAN FOR MANAGING MORQUIO A

You play an essential role in your Morquio A management. Together with your geneticist, complete the fields below to start your personalized management plan. Once you have your management plan, you should review it with your geneticist at least once a year. You may need to see other specialists not listed below as recommended by your healthcare team.

ORTHOPEDIST	Assessments | Frequency | Notes
Name: _____	
Phone number: _____	
Email: _____	

NEUROSURGEON	Assessments | Frequency | Notes
Name: _____	
Phone number: _____	
Email: _____	

PULMONOLOGIST	Assessments | Frequency | Notes
Name: _____	
Phone number: _____	
Email: _____	

CARDIOLOGIST	Assessments | Frequency | Notes
Name: _____	
Phone number: _____	
Email: _____	

OPHTHALMOLOGIST	Assessments | Frequency | Notes
Name: _____	
Phone number: _____	
Email: _____	

ENT	Assessments | Frequency | Notes
Name: _____	
Phone number: _____	
Email: _____	

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