

First International Workshop
Clinical practice guidelines on rare diseases
Rome , February 23-24, 2012

Contribution Round Table “Future steps for international collaboration”.
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Most rare diseases present in childhood and most children with chronic disabling conditions have a rare disease.

The European Academy of Paediatrics endorses the principles of chronic care management for children with rare and chronic conditions to:

- reduce fragmentation of care and
- enhance collaborative management involving patients, their families.

International Guidelines are an essential tool to achieve this goal because:

1. they help primary care providers identify persons at risk of rare disease
2. they can facilitate registration of ‘cases’
3. they can provide data for epidemiology and research
4. they can provide data on natural history; these data can be used when new diagnostics or therapies become available
5. they can provide tools for benchmarking
6. they facilitate collaboration on care between families, primary care and multiple specialists
7. they provide patients and families with information to make informed choices and the development of personal health records
8. they help patients and their physicians to advocate for better care and understanding
9. they reduce costs since at present individual countries are spending budgets by making national guidelines, often on the same diseases
10. they will provide small and /or low economy countries with guidelines, they will not be able to make on their own.

The development of these guidelines in Europe with its diversity in population size, economic status and health care systems of the individual states can contribute to a global approach.