

ORAL PRESENTATION

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Living with Progeria

Marjet Stamsnijder

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Children with Progeria can be an inspiration to those who meet them.

Mission

The Progeria Family Circle is a parents' organisation and network that supports European Progeria children and their families in several ways. The objectives are fourfold:

Meetings

First, the foundation organises annual meetings for all European children and their families. These are important highlights, because of the rarity of the disease children never see other patients. Also for the parents, mutual contact proved very valuable. Meetings are a source of joy in which the children find much self-esteem. Also they have the opportunity to speak with specialist physicians, and to exchange actual information about Progeria.

Information

As a second objective, the Progeria Family Circle offers parents of European children advice and support where needed. The value of emotional support and assistance of parents with experience is difficult to estimate. We bring family doctors and physiotherapists into contact with specialists in the field of Progeria.

Support

Progeria families come from different countries with different social, political and religious backgrounds. It is sometimes a big problem for families to give their children enough care. We also look for solutions to individual households to help them as directly as possible. If necessary, we seek financial support, when needed for the welfare of the child.

Medical developments

The fourth objective focuses on the medical field. The aim is to support better and faster recognition of symptoms and problems in new, but also known patients.

Scientific research and new therapies have made much progress in the past few years. An experimental treatment with Farnesyltransferase inhibitors (FTIS) started in Boston, and European children were offered a different therapy with a combination of statines and aminobiphosphonate in Marseille. The last combination of medication is also now used in Boston.

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Correspondence: marjet.stamsnijder@gmail.com
Progeria Family Circle, Nude 6, Rhenen 3911 VK, The Netherlands