Client Partner Profile guidelines

Partner Profile - Technical Information

A partner profile is to be produced under the following guidelines:
• Approximately 300 words per partner profile
• One main image, landscape
• One image of your logo
• Contact details of author including, name, organisation, e-mail and web address and phone number

The purpose of the profiles are to be informative to the reader:
• Areas of expertise: List/bullet points of core competencies
• Research interests: List/bullet point of key study areas

MPS Austria: champions of self-help support and research for therapy

Mucopolysaccharidoses (MPS) are slowly progressive and inheritable metabolic diseases and MPS Austria helps to improve quality of life for MPS patients.

MPS diseases occur in children of healthy parents and are triggered by a genetic defect that leads to disruption of protein function (‘enzymes’). These enzymes are needed in the cell to degrade the mucopolysaccharide. If they do not work properly, they accumulate in the cells and destroy them.

Although the children are completely healthy at birth, they soon lose their physical and/or mental development and develop severe disabilities. The shapes of the MPS are very different. The diseases can lead to bone changes, to the destruction of internal organs such as the heart, liver, and spleen, and can also lead to brain function disorders. Some patients become blind and many are hard of hearing. Almost all are short-lived.

Anyone with a child suffering from mucopolysaccharidosis is under great strain. It is not easy to find an answer to all the questions you suddenly have to deal with.

• What does the term “metabolic disease” mean?
• What will happen?
• What does “early death” mean?
• When will that be?
• Hereditary disease? Does not that mean the baby was born ill?