

**DECLARATION OF COOPERATION TO THE 101 GENOMES PROJECT DEDICATED TO MARFAN
SYNDROME OF THE 101 GENOMES FOUNDATION**

BETWEEN 101 GENOMES FOUNDATION

The 101 Genomes Foundation – Private foundation (F101G) was founded in November 2017. Its objective is to advance research by 10 years by creating a bioinformatics database containing complete genomic and phenotypic cross data of patients with rare diseases. This tool, which is accessible to the scientific community through a secure interface, aims to help improve understanding of rare diseases. The F101G pilot project is dedicated to Marfan syndrome. This is the **101 Genomes Marfan Project** (hereinafter P101GM).

The objective of P101GM is to cross-reference genomic and phenotypic data from a cohort of 101 patients with Marfan syndrome and make these data available to the scientific community to enable them to identify possible modifier genes that impact on major damage caused by Marfan syndrome. Such a discovery could make it possible to consider the development of new treatments.

The head office of F101G is located at 6 avenue de Sumatra, 1180 Brussels, Belgium.

It is represented by its President, M. Michel Verboogen.

Hereinafter referred to as **the Foundation**, of the first part;

AND THE PATIENTS ASSOCIATIONS

1) **The Luxemburgish Association “den-i asbl syndrome de Marfan”** (hereinafter den-i) is a non-profit organisation under Luxemburgish law whose objective is to inform about Marfan syndrome, raise awareness among the general public and support the people concerned. Its registered office is located at 58 Wisestrooss in L-3336 Hellange (R.C. F9386) in the Grand Duchy of Luxembourg. It is represented by its President, M. Denis Garzaro.

2) **The Association “Marfans”**, association under the French law of 1901, is the French association of Marfan syndrome and related disorders. Created in 1995, its main objectives are to support and inform families affected by the disease, in particular through its network of help and support (dating area) and its various publications and to support research. Its registered office is located at rue de la convention 121 in 75015 Paris. It is represented by its President, Mrs Stéphanie Delaunay.

3) **The Belgian Association “Association Belge du Syndrome de Marfan”**, a non-profit association under Belgian law. Founded in 1999, its objective is to guide and help people with Marfan syndrome and their families to resolve their moral and administrative difficulties, to participate in the dissemination of information about the syndrome, to promote scientific research and to establish contacts and exchanges with similar foreign associations. Its registered office is located at Rue du Beau Vallon, 176 in 5002 Saint-Servais. It is represented by its President Douchka Peyra

Hereinafter referred to as **the Associations**, on the other hand;

THE COOPERATION TO P101GM BETWEEN FOUNDATION AND THE ASSOCIATIONS INVOLVES:

1. The general promotion of P101GM by Associations to their members and to doctors and researchers working in the same territory;
2. The promotion of P101GM by Associations to encourage their members to join investigation or control cohorts;
3. The promotion of P101GM by Associations in order to encourage doctors and researchers working in the same territory to offer patients they follow to join investigation or control cohorts;
4. The promotion by the Associations of the Foundation's specific activities dedicated to the financing of P101GM;
5. The possibility, for at least, one representative of each Association to participate in the Foundation's activities (i) specifically dedicated to P101GM such as scientific committee meetings and occasional promotional events (scientific or philanthropic) and (ii) at the Foundation's annual General Assembly during which the progress of P101GM is discussed;
6. The participation of at least one representative of the Foundation in the activities of the Associations during which the P101GM would be mentioned, such as : (i) scientific conferences, (ii) annual general meetings at which the progress of P101G could be presented and (iii) specific promotional events (scientific or philanthropic) of P101GM organised by an Association;
7. Participation in an annual meeting of the signatories to this declaration;
8. The payment by the Associations of annual financial support to P101GM to the extend of their possibilities;
9. The mention of this declaration and its purpose on the respective websites of the Associations and the Foundation;
10. The systematic use of the logos of the Associations and the Foundation on communication material likely to contribute to the promotion of P101GM;
11. The parties may unilaterally decide at any time to terminate their cooperation on P101GM by communicating their decision in writing. Cooperation shall end on 31 December of the year in which the decision was notified.

The Parties confirm that this declaration of cooperation is intended to be ratified by the largest number of associations defending the interests of people with Marfan syndrome and related disorders.

Brussels, 5th October 2019.

For

101 Genomes Foundation

The Association den-i

Mrs. Ludivine Verboogen,
Board Member

Mr. Denis Garzaro,
President

The Association Marfans

The Association ABSM

Mrs. Stéphanie Delaunay,
President

Mrs. Douchka Peyra,
President