

Impatient crowdfunding

“Let’s fund groundbreaking research for Marfan Syndrome”

Concept note - 16th October 2019

Following our discussion in Drammen, we have decided to label the crowdfunding initiative as a “**Fondation 101 Génomes**” (**F101G**)’s fundraising project. We have called the project **Impatient**: a crowdfunding initiative geared towards groundbreaking research and precision medicine for Marfan Syndrome patients. We welcome the support of national Marfan associations and their members, families, friends and networks.

About F101G

1. **Medical scientists are discovering new ways to combat genetic disease.** The key to unlocking this potential are the recent **breakthroughs in understanding the human genome** – the complex relations between the thousands of genes that each individual carries, and that dictate so much of how each person’s body behaves.
2. **A group of world-class scientists in Belgium, France and The Netherlands want to understand why Marfan patients are so different from each other.** They want to know why the exact same mutation (i.e. one running in a family) can lead to severe symptoms in one person, and to mild symptoms or even no symptoms at all, in another. Scientists think that those people who seem healthy but carry the mutation may have something in their genetic make-up that makes them “immune” to the genetic disease. Scientists call this: protective “modifier genes”. In order to identify those “modifier genes”, **scientists need a special bioinformatic database** that crosses genomic information with clinical information of Marfan patients carrying the same mutation. **This tool does not yet exist.**
3. **F101G is a patient-driven initiative that aims to support the medical community by developing the database they need to accelerate research and develop precision medicine.** F101G has galvanised support from the medical community¹, the public sector, and technology providers. Over the past two years, F101G has raised over 500k€, including donations from the ABSM & Bindweefsel (Belgium), AssoMarfans (France), and den-I (Luxembourg). As soon as the ethical committee validates the methodology, top-notch biodata specialists will start developing the database. They will then launch amazing algorithms to discover modifier genes. Medical scientists are already working on research projects that will exploit the F101G database.
4. **Science is the history of people that have solved mysteries. Marfan patients can be part of this history by becoming active fundraisers for research.** F101G needs additional funds to pay for the

¹ The scientific committee is formed by scientists from Antwerp University, UZ Gent, Erasme Hospital, Nijmegen, Bichat Hospital.

genome-sequencing, and to maintain the bioinformatic database over the next 10 years. F101G strongly believes that a patient-driven initiative that is financially supported by a large group of patients is much stronger.

About Impatient

5. **Impatient is a patient-driven initiative that seeks to accelerate funding for groundbreaking research.** We want to boost medical research that leads to accurate diagnostic tools and more efficient treatments for people affected by Marfan syndrome. We are “impatient” because, when it comes to saving lives and improving the quality of life of patients, time is of the essence.
6. **Traditional funding in general, and for medical research in particular, is time-consuming and frustrating.** Public funding is shrinking, competition is fierce, big philanthropists are difficult to catch. Crowdfunding is an alternate idea to traditional funding: it allows many people to donate small amounts to the same cause. It also allows to raise substantial amounts of money in a relatively short period of time.
7. **Impatient wants to team up with Marfan associations and their members for three main reasons:**
 - We are convinced that this will make the campaign more effective: you can help us **identify local champions** (i.e. sparkles that will ignite the fundraising campaign in your countries).
 - Marfan associations have a very important role to play and **we want to support you:** Impatient could help you to diversify your sources of funding, boost your budget and expand the scope of your work.
 - Impatient could also help you **mobilise your members, their families and networks around a collective goal:** accelerating groundbreaking research and precision medicine for Marfan syndrome patients.
8. **Impatient proposes a joint crowdfunding effort.** We want everybody to feel comfortable and we are ready to explore “à la carte” solutions that are tailored to the specific needs of your association and to your expectations².
9. **Impatient’s crowdfunding campaign will be designed, launched and managed by professionals.** The team has a proven track-record, with more than 1.5M€ raised for charitable causes over the past two years. We want to develop a tool that is easy to use, and which ensures that payments are totally secure and fiscally deductible across Europe. A European campaign that generates positive energy and amplifies local champions in the Marfan community.
10. **Impatient wants to help F101G start its operations sooner** and to fundraise for complementary research projects that capitalise on F101G’s database. Impatient proposes that **all the funds raised**

² We can think of the following scenarios: (i) funds are split between the F101G and your association, based on a 50-50 key (but all funds go to F101G related or complementary research; (ii) funds raised go to your association who is responsible for transferring them to F101G integrally; (iii) all the funds raised in your country go directly to the F101G.

are used to fund Marfan-related research connected to F101G. We are convinced that this will **maximise our collective impact and ensure multiplier effects.**

11. **It is important that all donations are fiscally deductible.** We know from experience that this is essential to attract potential donors. In European countries where donations to Marfan associations are not fiscally deductible, donations could go directly to F101G, which benefits from fiscal deductibility in almost all European countries. F101G would then reallocate funds to the national Marfan association.
12. **Impatient and F101G are exploring the possibility to include a “donate a genome” dimension in the crowdfunding platform.** This part of the fundraising campaign is still under examination, but could be key to the success of the F101G: it will allow to expand its bioinformatic database including control groups. We are considering to replicate the model already tested by Spark for Autism (<https://sparkforautism.org/>) with great success³.
13. **Impatient could be the biggest patient-led crowdfunding campaign ever launched to fund research on genetic disease.** Impatient will reach out to other patient communities. Although F101G's pilot project is focused on Marfan Syndrome, F101G has the ambition to expand its focus to other rare diseases – potentially helping millions of patients.
14. **Impatient is a cooperative initiative that believes in collective action for the public good.** We estimate the cost of the campaign up to 30-60k€ (depending on the number of countries involved). We are already working on the platform because it makes us feel good and also because we know that professional fundraising campaigns yield good results on investment. We are actively approaching potential “impact investors” that could frontload investment. Impatient will also apply for a Belgian grant by Fondation Roi Baudouin. If, despite our efforts, these two strategies fail, F101G would fund the campaign by retaining a portion of the amount collected.
15. **Participating in the fundraising campaign will not cost your associations a single cent.** Your engagement would entail a commitment to: support F101G financially with the funds raised, help us identify local champions and connect with your members, help us translate, handle user support and fiscal deductibility, provide us with information for reporting. Impatient will be responsible for maintaining the platform and clearing payments, tailoring the campaign to different national contexts, ensuring optimal reporting to all donors, and disseminating learning to participating associations. Impatient will also deploy efforts to empower MEN members to become autonomous and effective crowdfunders.

³ Based on the *Spark for autism* model, the process could be summarised as follows: 1) Genome donors make a donation to F101G matching full sequencing costs. This donation is hence fiscally deductible. 2) Genome donors give consent to: (i) genome sequencing and access to their medical records, (ii) keeping their data during 10 years in F101G secured and pseudonymized bioinformatic database; (iii) conducting research on their data; (iv) being contacted if further investigations are needed. 3) Donors receive a special kit (saliva test) which is delivered through UPS to a laboratory for sequencing. 4) F101G pays the laboratory for sequencing and genomic data is stored in F101G database. 5) If duly justified (i.e. medical reasons) an access to a donors' raw genomic information could be provided to specialists authorized by the donor to carry out specific investigations. More information on this dimension can be delivered upon request.

Next steps

- 1st quarter 2020: Belgium will launch a prototype crowdfunding campaign.
- 2nd quarter 2020: based on lessons learned, Impatient will refine the prototype and scale up to other countries.
- FR/LUX/NL/AT have indicated interest in partnering with Impatient (depending on results achieved in BE, and if their board agrees).
- We will keep you informed along the way, and we will be happy to hear from you too.
- If you are interested to join Impatient, or if you know an energetic family that could help us launch a fundraising campaign in your country, please get in touch with Thomas and Alisa.
- If you want to be involved in other dimensions of the F101G, please contact Romain.

For more information, please get in touch !

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