GENERAL FORM - PATIENT
DISCOVER DYSPLASIAS PROGRAM

Program Summary

BioMarin International Limited ("BioMarin") with Europe, Middle East and Africa ("EMEA") regional offices in Ireland, is a subsidiary of BioMarin Pharmaceuticals, Inc., a North America based biopharmaceutical company that develops innovative therapies for rare genetic disorders. BioMarin (Data controller) is sponsoring a skeletal dysplasia genetic diagnostics panel in Europe and the Middle East wherein Blueprint Genetics will perform the clinical testing ("Program"). Blueprint Genetics (Data controller and data processor) is a genetic testing company based in Finland that has worked with clinicians in more than 70 countries. Blueprint Genetics provides clinicians and their patients with comprehensive and high-quality tools and resources for diagnosis of genetic conditions. Genetic diagnostics can reveal the underlying molecular cause of disease and improve patients' management, treatment, and follow-up care. By sponsoring the Program, the aim is to promote genetic testing for timely diagnosis of genetic skeletal dysplasias. Blueprint Genetics will not charge the clinicians or their patients for testing services as BioMarin will pay for the genetic diagnostics panel under the Program.
To obtain the genetic testing under the Program, the patient to be tested or the patient's legal representative must review and complete this form. The completed form will be returned to Blueprint Genetics with the specimen. Testing is completely voluntary and the decision to test is yours. You are encouraged to discuss the testing with your clinician to make informed decisions. Under applicable law, your clinician may ask you to complete additional consents and other forms.

By signing this form, you consent for Blueprint Genetics to collect your or the minor's blood, extracted DNA and/or saliva sample as per the clinician's request.

You confirm that you have provided true and reliable personal information, and fully understand the indication, intended purpose and potential risks of this testing. You also confirm that the information below has been explained to you and the following to be true:

1. **The clinician has explained the test to you and answered all your questions.**
2. **You understand that your authorization of the sample taken is voluntary.**
3. **The results of this test may show that you, or the minor you represent, has an inherited disease or is at an increased risk of being affected by a genetic disease. You understand that this test may detect previously unrecognized biological relationships, such as nonpaternity.**
4. **You are aware that the results of this test might be inconclusive. While some genetic variants are known to be disease-causing and others are known to be benign, a portion of genetic variants found are of uncertain significance. Depending on the results of this test, the clinician may recommend genetic counseling or further testing for you and/or other family members.**
5. **You consent to the processing of your sample and personal data as necessary to provide the test results to the ordering clinician.**
6. **If you are in the European Economic Areas or Switzerland, you understand that Blueprint Genetics and BioMarin are in a joint controller relationship to jointly determine the means of such processing. This consent can be revoked at any time by contacting support@blueprintgenetics.com or our Data Privacy Officer at privacy@blueprintgenetics.com. You can exercise your rights pursuant to Articles 12–22 of the General Data Protection Regulation by contacting Blueprint Genetics and also have the right to lodge a complaint with your local Data Protection Authority.**
7. **Unless otherwise required by applicable laws, Blueprint Genetics stores the sample for 12 months after submission of test results, and the related personal data for a maximum of 25 years. More information on data protection for this gene panel initiative can be found at: www.blueprintgenetics.com/discover-dysplasias.**
8. **You give permission to Blueprint Genetics to share identifiable personal data with BioMarin, which consists of: year of birth, residency country, details on the genetic findings, and laboratory ID. BioMarin will only use this personal data for the purpose of research and improving the services provided by Blueprint Genetics. Blueprint Genetics and BioMarin shall only process personal data in accordance with such party's rights and obligations. You understand that the aforementioned information may be transferred by BioMarin outside the European Economic Area in accordance with all applicable data protection laws. Where we transfer your personal information to external companies in other jurisdictions, we make sure to protect your information by applying all reasonable safeguards such as approved standard contractual clauses and appropriate security measures.**
9. **You understand that an anonymized summary of results from this test may be used by Blueprint Genetics in scientific publications and presentations and/or in DNA variant databases in order to improve the understanding, diagnostics, and treatment of similar clinical conditions. No identifying or identified personal data will ever be presented. BioMarin may collaborate with Blueprint Genetics for these publications.**

OPTIONAL: Consent for research use and long-term storage by Blueprint Genetics. By checking the relevant box below, you consent for Blueprint Genetics to use the sample and all results' information internally to improve the understanding of genetics behind skeletal dysplasias. This includes the long-term storage of the DNA sample in the diagnostic laboratory of Blueprint Genetics for the use of the DNA sample and the related data in the following:

- Scientific research to improve diagnostics and treatment of genetic skeletal dysplasias
- Research and development of diagnostic methods and products for genetic skeletal dysplasias

The research data concerning you or the minor you legally represent will be treated as confidential information and coded in such a way that your or the minor's identity cannot be discovered without the key code in possession of the Blueprint Genetics research physician. Where necessary, such coded research data may also be processed within or outside the European Economic Area and Switzerland as permitted by law and released for use by another research group or a company participating in the study. You consent to the use of your and the minor's data for research mentioned above for the purposes set out in this consent. Your sample and the related data will be preserved for longer than the standard consent, but up to a maximum of 50 years. You understand that if you have given an informed consent for research use of your or the minor's personal information by Blueprint Genetics, Blueprint Genetics acts as your data controller.

Your consent to the research use of the sample is voluntary, and you may cancel this consent and withdraw your participation in the research at any time before the completion of any study. The data collected up to the date of your withdrawal will be used as part of the research material. **Your refusal to take part in or withdraw from the research will not in any way affect the execution of the test requested by your clinician under the scope of the gene panel sponsored by BioMarin.**

Check one of the following two boxes: (If no box is checked it is assumed that no consent is given).

☐ **You consent to the research use and long-term storage of the sample as described above.**
☐ **You do not consent to the research use and long-term storage of the sample as described above.**

Items marked with asterisk are required.

SIGNATURE*:
PATIENT NAME*:
PATIENT DATE OF BIRTH*:
IF NOT SIGNED BY THE PATIENT, SIGNATORY NAME AND RELATIONSHIP TO PATIENT*: ☐ PARENT/LEGAL GUARDIAN ☐ OTHER, PLEASE SPECIFY NAME: