PATIENT CONSENT FORM

This form provides consent to share health information for the purpose of providing patient support and marketing or other communication.

zolgensma® (onasemnogene abeparvovec-xioi) suspension for intravenous infusion

To learn more about the OneGene Program®, call 855-441-GENE (4363), Monday-Friday (8 AM to 8 PM ET).

Enroll in the OneGene Program today by sending this signed Patient Consent Form by: Uploading online to www.zolgensma-enrollment.com
Mailing to OneGene Program at 600 Emerson Road, Suite 300, Creve Coeur, MO 63141 Faxing to 855-951-GENE (4363)

Consent to share health information for the purpose of providing patient support and marketing or other communication:

I hereby authorize my (and/or my child's) healthcare providers, health insurance carriers, and pharmacy providers to use and disclose my (and/or my child's) individually identifying health information, including health insurance information, medical diagnosis and condition (including lab test results related to such diagnosis or supportive testing), prescription information, and name, address, and telephone number to Novartis Gene Therapies, Inc. (hereinafter "Novartis Gene Therapies") and its agents and representatives, including third parties authorized by Novartis Gene Therapies to administer the OneGene Program, in order to administer the OneGene Program patient and ZOLGENSMA® (onasemnogene abeparvovec-xioi) support program for the following purposes: 1) to contact my (and/or my child's) healthcare provider and collect, enter, and maintain my (and/or my child's) health information in a database; 2) to contact my (and/or my child's) insurers as needed to verify my (and/or my child's) insurance coverage, review reimbursement requirements, and assist with the processing of claims; 3) to determine eligibility for program offerings, including financial assistance services; 4) to contact me by telephone or email, in electronic format or otherwise, to receive education, study the effectiveness of therapy, assess OneGene Program customer service, and to provide therapy support services designed for people prescribed ZOLGENSMA; 5) to occasionally contact me by mail, email, fax, telephone call, and text message for marketing or market research purposes and to provide me with information about program services and/or other topics of interest; 6) to perform data analytics with aggregated de-identified data to assess program efficiency; and 7) to provide the patient with ongoing therapy support. All prescription related support is limited to Novartis Gene Therapies product(s).

OneGene Program and Novartis Gene Therapies agree to protect my (and/or my child's) health information by using and disclosing such information only for the reasons listed above, pursuant to the requirements imposed under the Health Insurance Portability and Accountability Act of 1996 (HIPAA). I understand that federal privacy laws may no longer protect my (and/or my child's) health information after its disclosure to OneGene Program and that it may be subject to redisclosure.

I understand that I am entitled to a copy of this signed Authorization and may revoke (withdraw) this Authorization at any time by faxing a signed, written request to OneGene Program at 855-951-GENE (4363), uploading online at www.zolgensma-enrollment.com or by mailing such request to OneGene Program at 600 Emerson Road, Suite 300, Creve Coeur, MO 63141. OneGene Program will no longer seek disclosure of my (and/or my child's) health information from his/her healthcare providers and health insurance carriers once it has received and processed my revocation. However, revoking this Authorization will not affect any use and disclosure of the health information that has already occurred in reliance on my authorization. If I revoke this Authorization, I will no longer be able to receive OneGene Program support services.

This Authorization shall be valid for ten (10) years from the date indicated next to my signature below unless earlier revoked by my written request or in accordance with local laws.

No effect on treatment: I understand I do not have to sign this Authorization and that my enrollment in any of the services and/or programs described above is entirely voluntary. I understand that Novartis Gene Therapies, as well as my (and/or my child's) healthcare providers, cannot require me, as a condition of having access to medications, prescription drugs, treatment or other care, to sign this Authorization. Federal Law (including HIPAA) requires a signed authorization in order for OneGene Program to collect this information from my (and/or my child's) healthcare providers. I understand I cannot participate in the listed services and/or programs without signing this Authorization or an equivalent authorization with my (and/or my child's) healthcare providers.

I understand that my pharmacy, health insurers, and third party vendors may receive remuneration (payment) from the OneGene Program and Novartis Gene Therapies in exchange for disclosing my Personal Information to the OneGene Program and Novartis Gene Therapies and/or for providing me with support services for the purposes described above.

PATIENT INFORMATION

_____ _____/_____/_____
Patient Name (Please Print) **Patient Date of Birth**

_____ _____
Parent/Legal Guardian Name (Please Print) **Relationship to Patient**

SIGN

_____ _____/_____/_____
Parent/Legal Guardian Signature **Date**

_____ (_____)_____ (_____)_____
Parent/Legal Guardian Email Address (optional) Home Phone (optional) Mobile Phone (optional)

PRESCRIBER INFORMATION

_____
Prescriber Name (Please Print)

Please see Indication and Important Safety Information on page 2 and the accompanying Full Prescribing Information, including Boxed Warning for Serious Liver Injury and Acute Liver Failure.

Indication and Important Safety Information

zolgensma® (onasemnogene abeparvovec-xioi) suspension for intravenous infusion

What is ZOLGENSMA® (onasemnogene abeparvovec-xioi)?

ZOLGENSMA is a prescription gene therapy used to treat children less than 2 years old with spinal muscular atrophy (SMA). ZOLGENSMA is given as a one-time infusion into a vein. ZOLGENSMA was not evaluated in patients with advanced SMA.

What is the most important information I should know about ZOLGENSMA?

- ZOLGENSMA can increase liver enzyme levels and cause acute serious liver injury or acute liver failure which could result in death.
- Patients will receive an oral corticosteroid before and after infusion with ZOLGENSMA and will undergo regular blood tests to monitor liver function.
- Contact the patient's doctor immediately if the patient's skin and/or whites of the eyes appear yellowish, if the patient misses a dose of corticosteroid or vomits it up, or if the patient experiences a decrease in alertness.

What should I watch for before and after infusion with ZOLGENSMA?

- Infections before or after ZOLGENSMA infusion can lead to more serious complications. Caregivers and close contacts with the patient should follow infection prevention procedures. Contact the patient's doctor immediately if the patient experiences any signs of a possible infection such as coughing, wheezing, sneezing, runny nose, sore throat, or fever.
- Decreased platelet counts could occur following infusion with ZOLGENSMA. Seek immediate medical attention if the patient experiences unexpected bleeding or bruising.
- Thrombotic microangiopathy (TMA) has been reported to generally occur within the first two weeks after ZOLGENSMA infusion. Seek immediate medical attention if the patient experiences any signs or symptoms of TMA, such as unexpected bruising or bleeding, seizures, or decreased urine output.
- There is a theoretical risk of tumor development with gene therapies such as ZOLGENSMA. Contact the patient's doctor and Novartis Gene Therapies, Inc. (1-833-828-3947) if a tumor develops.

What do I need to know about vaccinations and ZOLGENSMA?

- Talk with the patient's doctor to decide if adjustments to the vaccination schedule are needed to accommodate treatment with a corticosteroid.
- Protection against influenza and respiratory syncytial virus (RSV) is recommended and vaccination status should be up-to-date prior to ZOLGENSMA administration. Please consult the patient's doctor.

Do I need to take precautions with the patient's bodily waste?

Temporarily, small amounts of ZOLGENSMA may be found in the patient's stool. Use good hand hygiene when coming into direct contact with patient body waste for one month after infusion with ZOLGENSMA. Disposable diapers should be sealed in disposable trash bags and thrown out with regular trash.

What are the possible or likely side effects of ZOLGENSMA?

The most common side effects that occurred in patients treated with ZOLGENSMA were elevated liver enzymes and vomiting.

The safety information provided here is not comprehensive. Talk to the patient's doctor about any side effects that bother the patient or that don't go away.

You are encouraged to report suspected side effects by contacting the FDA at 1-800-FDA-1088 or www.fda.gov/medwatch, or Novartis Gene Therapies, Inc. at 1-833-828-3947.

Please see accompanying Full Prescribing Information.

NOVARTIS

Bannockburn, IL 60015

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