CONSENT TO PARTICIPATE IN & AUTHORIZATION FOR PATIENT MENTOR PROGRAM FOR LUXTURNA® (voretigene neparvovec-rzyl)

Spark Therapeutics, Inc. ("Spark") created the Patient Mentor Program for LUXTURNA (the "Mentor Program") to connect patients who have been diagnosed with inherited retinal disease due to mutations in both copies of the *RPE65* gene with viable retinal cells or caregivers with patients who have been similarly diagnosed and subsequently treated with LUXTURNA for its indicated use (each, a "Mentor").

WHEREAS, I am a [patient/caregiver] who [has been diagnosed/cares for someone who has been diagnosed] with inherited retinal disease due to mutations in both copies of the *RPE65* gene with viable retinal cells (a "Mentee"); and

WHEREAS, I would like to participate in the Mentor Program and be connected by Spark to a Mentor.

NOW THEREFORE, in consideration of my participation in the Mentor Program, and without expectation of any other compensation or remuneration, now or in the future, I hereby agree to the following:

I. I give my consent to Spark to use my contact information with a Mentor along with introductory information, including, my age, my status as a patient or caregiver, my availability and my preferred method and time of contact (my "Information").

II. I understand and agree that:

   a. Spark's involvement in the Mentor Program is limited to introducing two people who share a similar experience with an inherited retinal disease ("IRD") as a Mentee and a Mentor.

   b. Spark will facilitate the exchange of Information between the Mentor and the Mentee prior to contact between the Mentor and the Mentee.

c. After facilitating the initial contact, Spark will have no involvement in the conversations or content between the Mentee and the Mentor. Spark is not responsible for the content or the quality of communications between the Mentor and the Mentee.

d. All conversations will be arranged between the Mentor and the Mentee.

e. Mentors may answer questions about their experience living with an IRD and their treatment with LUXTURNA; however, Mentors are not qualified to give and must not give medical advice. Mentors will direct a Mentee to speak with his or her healthcare professional regarding any medical information.

f. Mentors and Mentees should talk to their healthcare professionals if they have any medical questions about an IRD or LUXTURNA as a treatment option.

g. Participating or deciding not to participate in the Mentor Program will not affect a person's ability to receive treatment or the nature of treatment or care.

h. Mentors must meet the following criteria:

    - Treated with LUXTURNA for its indicated use at least three months prior to participating in the Mentor Program or cares for someone who has been treated in the last three months
    - Enrolled in Generation Patient Services
    - 18 years of age or older
    - United States resident

i. Mentees must meet the following criteria:

    - Diagnosed with inherited retinal disease due to mutations in both copies of the *RPE65* gene with viable retinal cells or cares for someone with this diagnosis
    - 18 years of age or older
    - United States Resident

III. In addition, I hereby agree not to disclose nor discuss my participation in the Mentor Program, including referencing being a Mentee, or participating in a Spark-sponsored program, in any social media channel or in any public forum (including with media outlets) outside of the discussions within the Mentor Program or those that may be requested by Spark.

IV. I agree that I will not make any legal claim in relation to privacy, defamation, any tort, or libel in relation to the use of the Information within the scope of this consent.

V. In signing this form, I authorize Spark to use and disclose all of my information, including my demographic information and my genetic results, for the following purposes:

- to provide me with education or marketing information about inherited retinal diseases and their treatments or to provide or offer information that Spark believes to be of interest to me
- for Spark's internal business purposes and analytics, including to analyze its patient population and evaluate and improve the patient support program
- to contact me via mail, telephone, in electronic format or otherwise, for the purposes described in this form.

I understand that this authorization is voluntary. I understand that I may revoke this authorization at any time in writing by sending a letter to Spark at Spark Therapeutics, 3737 Market Street, Suite 1300, Philadelphia, PA 19104, Attention: Spark Patient Services. Revoking this authorization will prevent Spark from using or disclosing my information for the purposes set forth in this authorization but will not affect the uses and disclosures of my information that were already made in reliance on this authorization. I understand that I may ask to be forgotten by requesting in writing at the above address that all of my information be deleted and erased.

I understand that once my information has been disclosed, federal privacy laws may no longer apply or protect the information from further disclosure. Unless I expressly revoke this authorization, it shall remain in effect for five (5) years from the date I sign below. I will obtain a copy of this authorization for my records.

I agree to be contacted by Spark via mail, email, and telephone calls made by using an automatic telephone dialing system at the number(s) and address(es) I have provided on this form for all marketing and non-marketing purposes described. I confirm I am the subscriber for the telephone number(s) provided and the authorized user for the email address(es) provided, and I agree to promptly notify Spark of any number or address changes in the future. I understand that my wireless service provider's message and data rates may apply.

Understanding this Consent:

- My decision to sign this authorization will not affect my ability to get care or participate in any clinical trial or other programs sponsored by Spark.

Signature: _____

Name of Participant: _____
(print)

Age: ___

Phone: _____

E-mail: _____

Address: _____

_____

Date: _____

Fax the completed consent form to 1-678-727-1501 or email to mysparkgeneration@sparktx.com