



Association
Syndrome
de Wolfram



hope
eye hope foundation



SNOW FOUNDATION
FOR WOLFRAM SYNDROME RESEARCH
A GLOBAL VOICE FOR RARE DISEASE

TERMS & CONDITIONS

Association syndrome de Wolfram, Eye Hope Foundation and Snow Foundation (hereinafter, the WS-organizations) are not-for-profit organizations dedicated to the fight against Wolfram syndrome. Our primary mission is to support and accelerate research, for the development of treatments against this orphan disease. In this perspective, Association syndrome de Wolfram, Eye Hope Foundation and Snow Foundation finance and co-finance research projects contributing to the pursuit of this mission.

Article 1 – Parties to the agreement

An agreement, including the present 'terms & conditions' document and a document drawn up in the name of the Beneficiary, is established between each individual WS-organization and the Beneficiary.

Article 2 – Purpose of the agreement and of the financial support

In accordance with the conditions, financial support is granted to the Beneficiary. The project on which this financial support is based is described in detail in the application form. The latter is thus an integral part of the agreement. The financial support consists of a fixed amount and includes all fees and VAT.

Article 3 – Methods of payment

The WS-organizations will make available the financial support in accordance with the methods of payment indicated below and in conformity with the conditions outlined in the document drawn up in the name of the Beneficiary.

- All payments will be made upon the presentation of a payment request, of which there is a sample annexed;
- In the event of a payment in several instalments, the Beneficiary will, for each instalment and on dates agreed upon, send a payment request to each individual WS-organization;
- The first, or if applicable, the only payment will be made as a deposit;
- Any amounts paid to the Beneficiary can be reclaimed in whole or in part if the Beneficiary finds it impossible to complete the project;
- The payment will be made 30 days after the end of the month of the date of receipt of the payment request.

Article 4 – Report and evaluation

The Beneficiary undertakes to provide, within the time period set out in the document drawn up in its name, activity and financial reports concerning the execution of the project, to which the present agreement pertains, and concerning the usage of the financial support. The Beneficiary agrees to collaborate in any evaluation on request of the WS-organizations. For example, regular update meetings (face-to-face or teleconference meetings) will be organized between the three WS-organizations and the principal investigator. The frequency of these meetings will be agreed by the WS-organizations and the principal investigator prior to the project launch.

Article 5 – Communication

The Beneficiary undertakes to mention the support of the WS-organizations in any public communication associated with the project as outlined in this agreement; unless otherwise agreed, the following phrasing shall be used: ‘project carried out with the equal support of the Association syndrome de Wolfram, the Eye Hope Foundation and the Snow Foundation’.

Article 6 – Modifications and disputes

All correspondences pertaining to the present agreement comprising modifications and/or supplementary agreements shall be considered to form part of it once each of the parties concerned as agreed to and signed these documents.

The parties undertake to assiduously execute this agreement and, in the case of disputes, to seek an amicable solution as a matter of priority. In the case of a legal dispute, the courts and tribunals designated by the WS-organizations shall prevail.

Article 7 – Termination

Should the Beneficiary no longer be able to continue the project, it will inform each WS-organization and will submit a report on the status of the project. In such case, only the services already carried out will be indemnified. Similarly, the WS-organizations will have the right, in proportion to the progress of the project, to reclaim all or part of the amount already paid.

Article 8 – Privacy

The Beneficiary authorizes the WS-organizations to include in their annual report, their newsletters, on their internet website the following information: the Beneficiary contact details, the amount of the financial support and a short description of the project.

Article 9 – Illustration

Within six months of conclusion of this agreement, the Beneficiary shall forward to the WS-organizations one or more photos illustrating the funded project (digital format or paper). It is important for the Beneficiary to mention the name of the photographer and for the persons photographed to have agreed to the use of their photo to illustrate the WS-organizations’ websites or annual report, regional reports, newsletters or other publications. The WS-organizations agree not to transmit the photos submitted to third parties. The WS-organizations will always mention the name of the photographer or the organization when using an illustration.

AGREEMENT

You have received two copies of the present agreement. One copy is for you to keep. Please sign the second copy and return it, duly completed and signed to the *[Association syndrome de Wolfram or Eye Hope Foundation or the Snow Foundation – followed by address]*.

The Beneficiary will have to sign this agreement with each WS-organization individually (meaning that 3 agreements will be signed in total for the same project).

An agreement is established between

[The Association syndrome de Wolfram or the Eye Hope Foundation or the Snow Foundation], a not for profit organization whose headquarters are located at *[address]* and represented by *[Nolwen Le Floch, Founder and Vice-President or Lode Carnel, Founder or Stephanie Gebel, Founder and President]*

And the Beneficiary

[Institution]

[Address]

Holder of the account *[account number, bank name]*

Represented by *[name and title of the Beneficiary representative]*

The *[WS-organization]* grants financial support to the Beneficiary, in accordance with the specific terms and conditions, on which the Beneficiary agrees.

AMOUNT and payment of the financial support

The *[WS-organization]* will support the Beneficiary's project for a total and fixed amount, all fees and VAT included of:

- ***[amount in numbers in euros or in USD]***
- ***[amount in letters]***

This amount will be allocated for carrying out:

- ***['title of the project']***
- ***[short description of the project]*** by *[prof/Dr name family name, division/department, institution, location]*

This Agreement is effective for the period *[date]* through *[date]* and may be extended only by written agreement of the parties.

This amount will be paid by the *[WS-organization]* to the above account in *[1 or 2]* installment(s), as follows:

- The first installment will be paid by the *[WS-organization]* within a period of 30 days following receipt of the signed agreement and the duly completed and signed payment form. These documents must be sent to the *[WS-organization]* at the latest within 4 months from the date of sending the agreement. After that date the agreement will be null and void.
This amount will be definitely acquired after approval by the *[WS-organization]* of an intermediate activity report and a detailed financial report which it must receive at the latest on the *[date – end month 11]*.

- The second installment will be paid by the [WS-organization] within a period of 30 days following receipt of the duly completed and signed payment form.
This amount will be definitely acquired after approval by the [WS-organization] of a final activity report and a detailed financial report which it must receive at the latest on the [date – end month 25].

CONDITIONS to carry out the payment of the financial support

- Terms and conditions: see annex 1
- Specific conditions:
 - o When the principal investigator of the supported project can't continue on the job, the agreement will be suspended. The agreement can only be continued after the explicit agreement of the responsible person at the [WS-organization].
 - o Regular update meetings (face-to-face or teleconference meetings) will be organized between the three WS-organizations and the principal investigator. The dates of these meetings will be the following: [dates]
 - o The [WS-organization] contributes [amount in numbers] to [Beneficiary]. This contribution is to support research efforts as it relates to Wolfram syndrome at the discretion of [prof/Dr name and family name] at the [name of division/department]. For recognition purposes, please list in publications as [name of WS-organization].

Done in two original copies in [location], the [date]. Each party declaring it has received its respective copy.

[Name, Family Name]
[Title]
[Name of Beneficiary]
[Country]

[Name, Family Name]
[Title]
[WS-organization]

[Name, Family Name]
[Title]
[Name of Principal Investigator]
[Country]

Should you experience any problem or have further questions, please contact [name of contact], email: [email].

Annexes:

- Terms & Conditions

- Payment Form
- Project (application form)
- Budget
- Evaluation report