



End of year report

2015 Project

**FONDATION ARTHRITIS**

**Lupus Makeup Lessons**



## Project details

1. Please summarise in a few words the project supported by TFWA CARE, including the principle objectives and duration.

The project “lupus makeup lessons” is fully integrated in the lupus BASIC campaign that aim at improving the outcomes of lupus patients, both in terms of morbidity/mortality survival and of quality of life. Each items of the BASIC acronym is a target axis of our program, chosen because of the high impact in terms of outcome in the lupus patient population.

The current project aim was to develop educational interactive supports to improve knowledge and strengthen the self-confidence of these lupus patients with regard to the control of UV exposition and skin care.

Ideally, these tools would be used in therapeutic patient education programs dedicated to lupus patients in France and their impact in terms of quality of life in these patients would be evaluated.

The project started in 2014 and its objectives will be accomplished by the beginning of 2016.

2. What activities were carried out within the scope of the project over the course of the year?

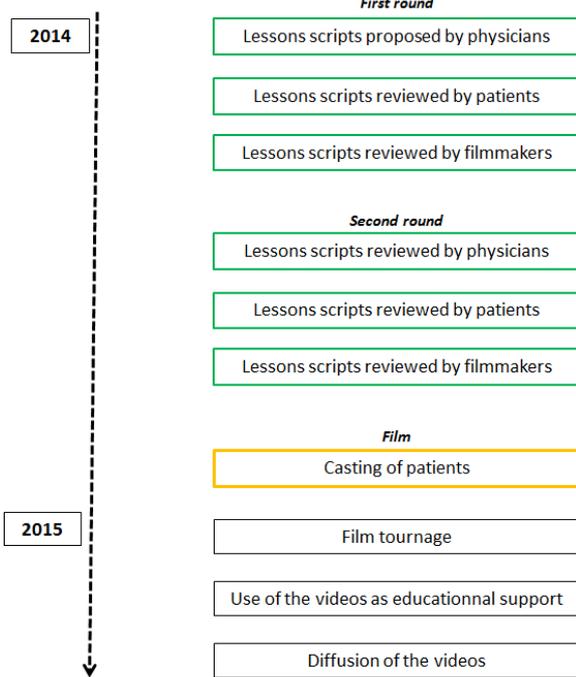
The complementary activities were, in chronologic order:

- 1- Finalization of the movie “lupus beauté institut” and related short videos/tutorials.
- 2- The large diffusion of these videos via the Web (youtube channel)
  - a. Relayed by patients association website (AFL) to their adherent
  - b. Physicians website
  - c. DVD diffusion to all expert centers in France through 2 keys events:
    - i. the national meeting of specialists in internal medicine (Tours, SNFMI, December 2015)
    - ii. the national meeting of French lupus experts (Paris, January 2016)
- 3- The development of “ateliers” of therapeutic education in a referent center (Hopital European, Marseille) with a “patient expert” to evaluate the new educative tools before a dissemination to other centers.
- 4- The dissemination of the BASIC concept through
  - a. BASIC Flyers for referent centers to give to their patients

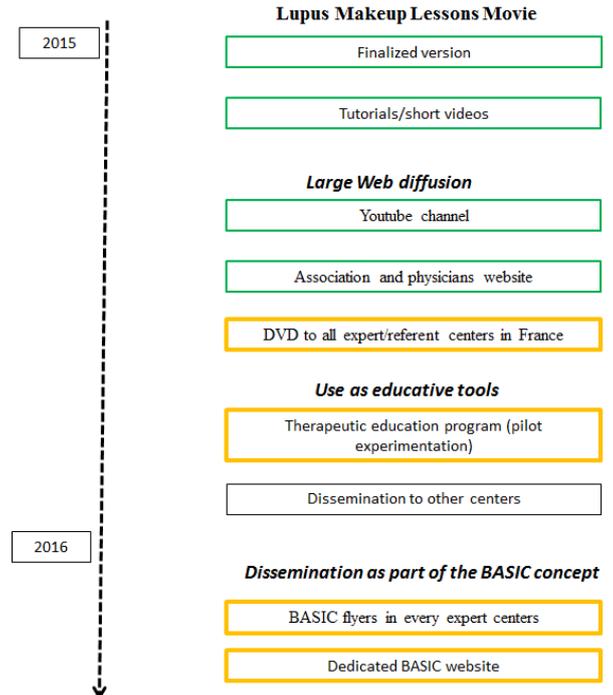


- b. A dedicated Website that will be launched to the medical community during the 2 events mentioned above and through the FAI2R filière.

Last year report



This year report



(in green: done; in yellow: ongoing)



## Evaluation

3. Has the project been successful? Please outline the success factors for each objective as well as the challenges encountered and solutions adopted to overcome them.

Yes. Success factors: strong involvement of both patient associations (Association France Lupus) and the new French filière de santé for autoimmune rare diseases (FAI2R). During the project, mainly because of the feedback of some patients involved, the team rapidly became convinced that the more efficient way to diffuse the work done to the largest proportion of patients would be the web, so that effort were concentrated on web tools (youtube chanel, website etc...) instead of producing high number of DVD. The success of this choice is reflected by the rapid and growing number of view of the youtube videos or related article on the websites of patients associations.

4. Did the work accomplished this year help you learn lessons that will benefit future work?

Yes, an involvement of patients as early as possible in the initial steps of any patients targeted project to come. Also, across numerous patient participation to the first session of therapeutic education, we could identify that patient had difficulties to identify situation at risk of higher UV exposure. This was the rationale for the next project (see SUNSET project below).

## Sustainability

5. How has the project had a positive impact on the community/ies at the core of the project and what will be the long term benefits? Please explain if the project has helped empower the beneficiaries by providing greater autonomy.

Video supports have already been used in the context of a therapeutic educational program in one center (Marseille). The best feedback was from one of our patient that decided to use them to build a local program of "makeup lessons" in this center. This local initiative is about to start officially and will be evaluated to be, hopefully, transposed in other centers around France.



6. Will the project continue in the future or is it now complete? Will further funding be required in the future to complete the work? Please indicate if the initial funding request was a multi-year project. \*\* (see footnote)

The objective of the Lupus Makeup Lessons project was to develop videos as educational support for patients suffering lupus. We aimed at disseminating and evaluating the use of this new support within therapeutic patient education programs. Finally, as all lupus patients are not involved in such programs, we also aimed at developing a website to propose online education of these patients. Further funding may be required to complete the development of this new website and for the evaluation of their educational impact on patients. A new project to be funded will be submitted to TFWA CARE in 2016.

## Finance

7. Please provide a summarised breakdown of how TFWA Care funds were utilised for the project.

The budget hasn't changed from the provisional budget. The budget of 2014 and 2015 were utilized for:

The movie  
DVD and Flyers  
The Website

Please attach your latest annual report as well as any pictures you would like to use to illustrate this report.

We would be grateful if you could send this to John Rimmer ([j.rimmer@tfwa.com](mailto:j.rimmer@tfwa.com)) by **November 6 2015 at the latest.**

\*\* If you would like to submit a request for further funding for a **new project** to be funded by TFWA CARE in 2016, please complete the form on the following page.

## DEVIS 0376

## GUIDE LUPUS + CREATION SITE WEB

DESCRIPTIF

CÔÛT

**DIRECTION ARTISTIQUE & EXECUTION GUIDE**

Réalisation d'un guide pour la formation des maquilleuses dédiées aux patients atteints de lupus d'une cinquantaine de pages

Recherche typographique et illustrative  
 Corrections allers-retours  
 Mise à l'exécution des fichiers  
 Préparation des fichiers pour l'imprimeur

3 500,00 €

**IMPRESSION**

Int : 52 PAGES  
 Format : 148 x 210 mm  
 Exemplaire : 100 ex  
 Papier : 115gr splendorgel  
 Impression : Recto/Verso  
 Couleur : Quadri

COUV + 1 rabat au dos  
 Format fini : 148 x 210 mm  
 Exemplaire : 100 ex  
 Papier : Couché mat 250gr  
 Impression : Recto  
 Couleur : Quadri

+ Livraison à Marseille

1 920,00 €

**DESIGN SITE INTERNET**

Design de l'ensemble des pages nécessaires, conception du site

3 000,00 €

**DÉVELOPPEMENT SITE INTERNET**

## SITE INTERNET

## INTEGRATION

Création de la structure  
 Création d'un plan d'accès

## DEVELOPPEMENT

Création de 15 pages fixes (selon votre cahier des charges)  
 Création d'un outil de visualisation de fiche à double tri. Par pièce et par lieu.

## ADMINISTRATION

Installation de l'administration  
 Gestion des utilisateurs  
 Ajout modification et suppression de fiches.  
 Les fiches :  
 Titre, description, date, photos 10, vidéo.

4 800,00 €

**GESTION DE PROJET**

Réunions, présentations, respect des délais, gestion impression et fournisseurs

900,00 €

**TOTAL HT**

14 120,00 €

**TOTAL TAXES (19,6%)**

2 767,52 €

**TOTAL RÉALISATION TTC**

16 887,52 €

## Flyers

## BASIC c'est quoi ?

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C'est tout ce que vous avez toujours voulu savoir sur le Lupus sans jamais oser le demander.

Que faut-il faire avant d'avoir un **BÉBÉ** ?

Pourquoi il faut faire attention à ses **ARTÈRES** ?

Pourquoi faut-il absolument se protéger du **SOLEIL** ?

Comment gérer les risques face aux **INFECTIONS** ?

Quels sont les effets secondaires sous **CORTICOÏDES** ?

Venez trouver des réponses sur  
**LUPUSBASIC.COM**

# BASIC

## DU LUPUS

LE NOUVEAU  
**SITE**  
EST EN LIGNE



**LUPUSBASIC.COM**

## DVD

# LUPUS

## BEAUTÉ INSTITUT

Christine, patient-expert et meilleur ouvrier de France en Esthétique et Art du Maquillage donne 3 leçons de maquillage et conseils beauté pour mieux vivre au quotidien avec son lupus.



**BASIC**  
DU LUPUS

**LUPUSBASIC.COM**






# LUPUS

## BEAUTÉ INSTITUT

**LUPUSBASIC.COM**



## Website



# BASIC

## Les principes Basic

A travers ce carnet de suivi, nous avons souhaité proposer aux patient(e)s une démarche interactive et active, pour les guider dans l'élaboration d'un suivi personnalisé et complet de leur maladie lupique.

Dans ce carnet, les mesures dites « associées au traitement » sont mises en avant car trop souvent les grandes « oubliées ». Elles sont pourtant de nature à influencer votre devenir à court, moyen et long terme (1).

5 axes ont été choisis sous la forme de l'acronyme « B.A.S.I.C. », pour permettre aux médecins et aux patients d'aborder

BÉBÉ

ARTÈRES

SOLEIL

INFECTIONS

CORTICOIDES

## Movie



# LUPUS BEAUTÉ INSTITUT



LUPUS BEAUTÉ INSTITUT

BÉBÉ

ARTÈRES

SOLEIL

INFECTIONS

CORTICOIDES



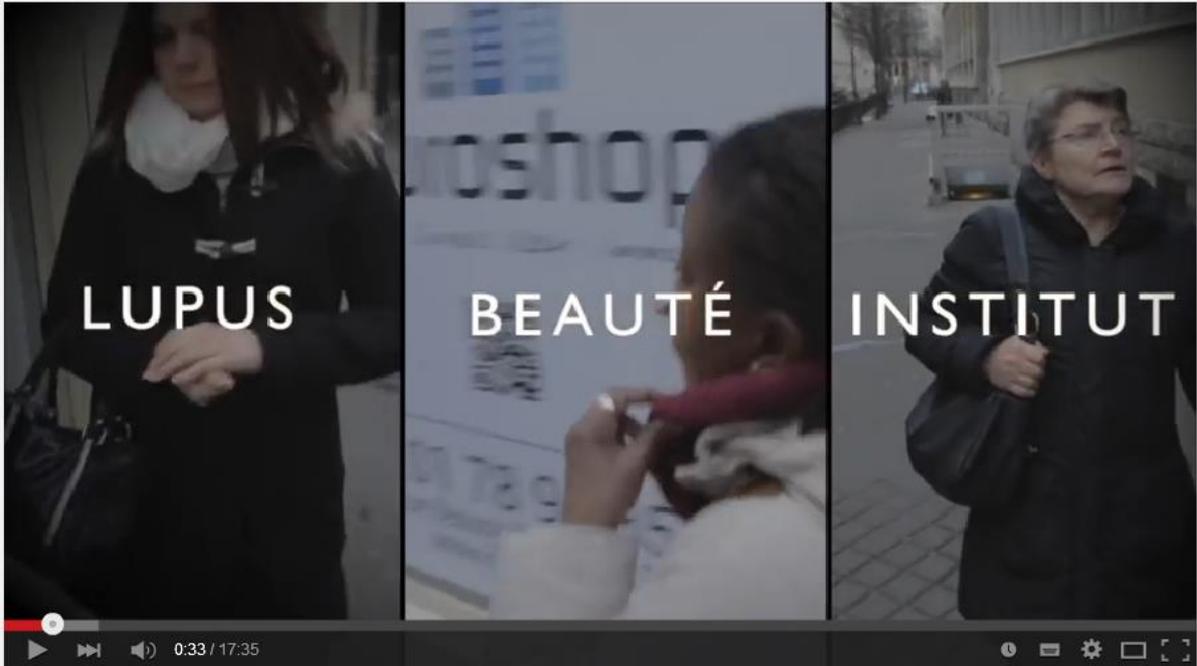
PARTENAIRES



TFWA

CARE

YouTube FR



LUPUS BEAUTE INSTITUT



## **New project submission for 2016**

### Project description (activities and objectives):

In the continuity of the Lupus Makeup Lessons project, the Lupus Sunset (SUN Smartphone-controlled Exposure through a dedicated Tool) project propose to help lupus patients to evaluate themselves their objective exposition to UV to help them to put into application the photoprotection measures learned during the Lupus Makeup lessons. This project involves smartphone-related devices to be able to provide 2.0 medicine to lupus patients.

Duration of project: one year with the inclusion of 30 SLE patients.

### Cost (please provide skeleton budget):

We want to use a device-dosimeter (SHADE) provided by the team of Emmanuel Dumont (The Technion-Cornell Jacobs Institute). It is easily fixed to clothes with a magnet. The device has a microprocessor for collecting data from all the sensors and sends the data to the patient's smartphone via Bluetooth. The device is powered by a rechargeable battery for approximately one week of battery life and is rechargeable with a micro-USB cable. The optical design and electronics of the device corresponds to a similar UV detection accuracy that can be obtained using spectrophotometry techniques.

The budget including the purchase of specific devices and the development of a "lupus" smartphone application is valued at 17 330 euros HT.

<b>Devices</b>	
Number of devices	30
Cost per device	375 €
Total cost	11 250 €
<b>Design of mobile application</b>	
Person	Mary Nachimov
Rate (/hour)	38 €
Estimated number of hours	40
Total cost	1 520 €
<b>Coding of mobile application</b>	
Company	Etasha technologies
Rate (/hour)	19 €
Estimated number of hours	240
Total cost	4 560 €
<b>TOTAL</b>	<b>17 330 €</b>

Financial support sought from TFWA and % of overall project cost:

(If a multi-year project, please indicate annual funding requirement sought)

100% of cost is sought from TFWA: 17 330 € for the year 2016

Organisation annual budget (revenues):

1.7 M€ : 800 K€ donations go to Research, 700 K€ of sponsored events for communication and patients' formation, 200 K€ operating costs

Percentage of administrative costs for main organisation as part of overall budget:

(Administrative costs for running the organisation eg. marketing, fundraising, management etc)

100% of administrative costs are supported by CLARINS (200 K€ = 11,8% of total budget)

Other sources of funding for this project:

The other costs of the study (including time for research assistants) are provided by the study sponsor (European Hospital of Marseille).



Please explain, in a few brief words, how the work carried out helps the local community, to what extent it enables the beneficiaries to become more self-sufficient, and any other relevant information you wish to share.

Systemic Lupus Erythematosus is an autoimmune condition with frequent cutaneous involvement. Photosensitivity is one of the hallmarks of SLE with an increased risk of flare after UV exposition. Some patients do not avoid sufficiently sun exposition because their perception of UV exposition is often wrong. One of the ways to help them induce a change in their sun-related behavior may be to provide them with objective measures of UVR exposure. Medical smartphone applications seem to be very useful in new health management model, especially in chronic diseases. The feasibility of using smartphones connected UV dosimeters as a collecting tool on a daily basis to evaluate UV behavior has been demonstrated recently. The study aims to assess the subjective perception of UV exposure in SLE patients before and after the use of a personal UV dosimeter.