

# Live Now Charity Foundation

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REPORT ON THE WORK OF THE FOUNDATION IN  
JANUARY-OCTOBER, 2016



# About Live Now Charity Foundation

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The Foundation was started in 2015 on the initiative of people with ALS and their families, as well as doctors and those who help.

We support people across the whole Russia in a format that is available in different regions.

We will do our best to improve the lives of people with ALS, so they can get the best possible care and die with dignity.

Goals of Foundation's work :

- To facilitate the lives of people diagnosed with or presumed to have ALS. At that time our aim is that people with ALS and caregivers could receive that volume of aid, which is possible in their circumstances.
- To bend every effort for researches aimed at finding the ALS causes as well as a possible treatment for the disease.

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# The team in Moscow and St. Petersburg: Foundation, two ALS services are volunteers



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# The team in Moscow and St. Petersburg: Foundation, two ALS services are volunteers



66 people are experts and volunteers who cooperate with a Live now Charity Foundation and/or help people with ALS and their families in ALS services in Moscow and St. Petersburg

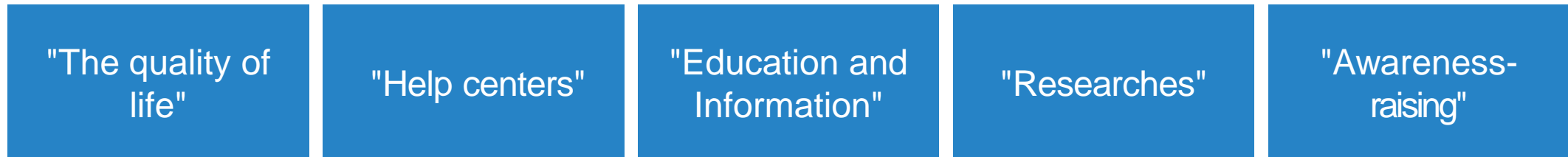
# Structure of the Foundation

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## Controlling bodies



## Programs



# Main events for 10 months

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DURING THE YEAR WE HAVE THE ONGOING WORK WITH PATIENTS, AND THERE ARE SEPARATE EVENTS AND INITIATIVES THAT WE ORGANIZE FOR DEALING WITH DIFFERENT ISSUES



# Main events

# 2016

February



We held a three-day seminar with international participation for the ALS service and Foundation team. There were 50 participants, 15 of which were speakers

Together with the School of Dramatic Art we invited ALS patients and people with other serious diseases, as well as their relatives to the play "Earl Nulin"

March

We held a Second patient conference on ALS, which was addressed by speakers from different regions and attended by more than 100 people

In the follow-up process the Council of families appeared in the Foundation, whose task is the development of private fundraising and support of patients

April



We were co-organizers of the interdisciplinary symposium "Death and dying in modern Russia. How to start to talk about the importance?"

We held a seminar on occupational therapy for ALS service employees, we learned at the seminar how to set goals by organization of care for people with ALS

Doctors, nurses and coordinators of service completed training on communication in difficult situations

We started a research on the effect of stress on the development of ALS

# Main events



May

We went to the Great Britain at the invitation of the British ALS Association, visited ALS Center, communicated with colleagues, learned how the care in UK is organized.

We performed an audit of nursing homes in Moscow and Moscow suburbs.

We took part in the seminar of the European Network to Cure ALS (ENCALS)

We held a week-long training and traineeship for colleagues from St. Petersburg and Latvia

June

Together with Miloserdie.ru we held a round-table discussion "Fatal diagnosis: the right to be the first know to know"

We launched the School for Nutrition for people with ALS, their relatives and caregivers

Together with a guide Irina Chichkina we organized a Moscow tour for people with ALS and their families

We held the "Cornflower picnic". It was the first event of the Council of families with ALS

Together with the project "Moscow which doesn't exist" we organized three excursions during June, partial funds raised from them went to ALS patients

We helped to organize the participation of ALS patients and their families in the liturgy in the church of the Intercession of the the Convent of Martha and Mary on the ALS Day

Together with the company Clarins we held master classes for women with ALS in make-up and skin care at the «School of beauty».



July

We organized the first polyclinic reception of patients with ALS in St. Petersburg — together with the initiative group of relatives of patients and professionals, with the support of the association GAOORDI.

We agreed a partnership with the service "Clear morning" for people with ALS and their families to be able to receive psychological support on the Hotline

# Main events



August

We held a training "Music volunteering in the system of palliative care for adults". The group was formed of volunteers who will be able to help the tens of patients with palliative diagnosis

The second special excursion "Literary Zamoskvorechye" was held for people with ALS, their families and friends

We went to Berlin and talked in the clinic Charité to Professor Muller, a leading ALS expert in Germany

September

We opened palliative care department for neuromuscular patients on the basis of the Central Clinical Hospital named after Holy Hierarch Alexis (CCH MP)

We went to Milan and talked to the medical director of the ALS nurse/home-based care service, as well as to the professor who directs the major respiratory center

We launched a working team to create an algorithm of management for patients with ALS, which will become the basis for documents of the Moscow health department

October

We took part in the round table discussion on pain treatment, raised the question on unavailability of morphine

We participated in the polyclinic reception in St. Petersburg, organized a consultation of palliative care doctor



# The Foundation's key projects status

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PROJECTS ACT UNDER THE FOUNDATION'S PROGRAMS,  
THEY ARE AIMED AT THE SYSTEM SOLUTION OF  
DIFFERENT PROBLEMS

# Development of the algorithm on the care delivery by ALS

PROGRAM: "Help centers"

TEAM:

Egor Larin, Lev Brylev, Anna Kasyanova, Faina Mudzhabaeva, Yaroslava Krasnaya, Olga Beketova

## WHAT FOR PROBLEM IS BEING SOLVED

There is no protocol on management for patients with ALS, so even in situations when the patients are received by medical institutions, they do not receive adequate assistance.

## EXPECTED RESULTS

The algorithm will be developed. On the base of it a number of documents will be drawn up in the Moscow health care system.

## PROJECT SUMMARY

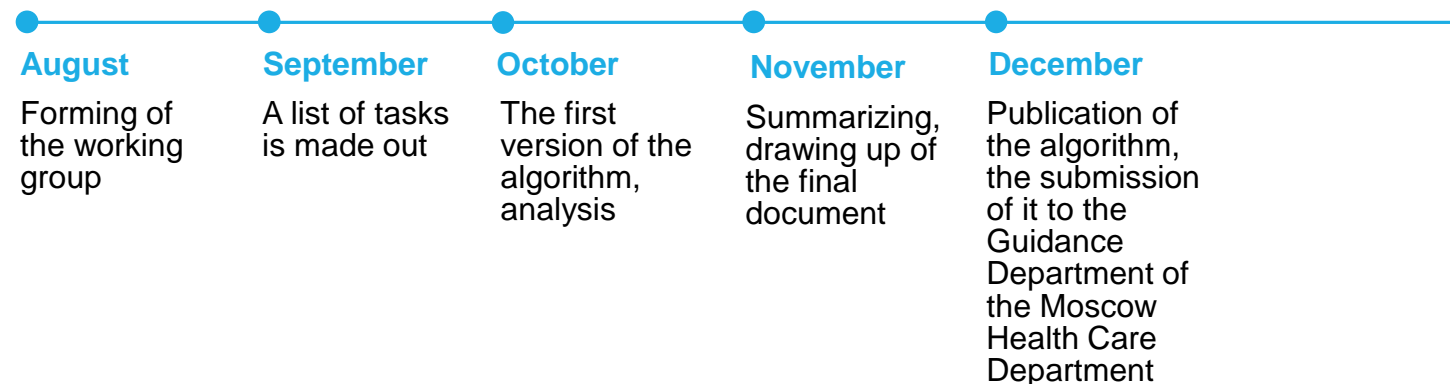
A working group was created, which included representatives of different specialties, who have an experience in the care delivery to people with ALS in the Moscow at the ALS service, as well as people with experience of work in the social assistance system and the Methodist of the Moscow Health Care Department.

The working group also uses international protocols for management of patients with ALS, as well as the information we have received in the UK, Germany and Italy.

Within the working group, a multi-disciplinary experience in Russia and abroad will be analyzed to create an adequate algorithm for management of patients and also to implement it in the future to the health care system.

## KEY STAGES

2016



# Opening of hospital-based care department for ALS patients in Moscow

PROGRAM: "Help centers "

TEAM:

Lev Brylev Egor Larin, Anna Kasyanova, Vadim Parshikov, Alexey Zarov (acting chief physician of CCH MP), Natalia Semina

## WHAT FOR PROBLEM IS BEING SOLVED

The absence of hospitals, which would receive ALS patients in connection with the primary diagnosis.

## EXPECTED RESULTS

In 2016 the palliative department will be opened on the basis of the Central Clinical Hospital named after Holy Hierarch Alexis Metropolitan (CCH MP) in Moscow for patients from Moscow and regions.

## PROJECT SUMMARY

It's necessary to open departments on the basis of several hospitals in Moscow, in which the ALS patients could be hospitalized for observation under their main diagnosis. One hospital is a Palliative department in Central Clinical Hospital named after Holy Hierarch Alexis (private health care facility), where patients from the regions also can be hospitalized. The department may operate as a respite to give families an opportunity to rest. Also, on the basis of the department it's planned to hold trainings for relatives and caregivers.

Negotiations are being carried with Moscow Health Care Department about other hospitals.

The task of the Foundation in this project is to agree with all parties on how to open these departments and to take care on partially financing of their work, provided that the patients will be observed in accordance with the guidelines on giving care to ALS patients.

## KEY STAGES

2016

August

We agreed with CCH MP on the opening of the palliative department for ALS patients

September

ALS Service moved to CCH MP

October

Hospitalizations to the palliative department of CCH MP started

December

The signing of agreements with hospitals on conditions of hospitalization of patients with ALS

2017

during the year

Optimization processes

Supervision

Adjusting agreements

Opening of one more department

# Opening of the assistance service for people with ALS in St. Petersburg

PROGRAM: "Help centers"

TEAM:

Anna Kasyanova, Lev Brylev,  
Natalia Semina, Vera  
Demeshonok, Margarita  
Urmancheeva

## WHAT FOR PROBLEM IS BEING SOLVED

Number of patients with ALS in St. Petersburg amounts about 500 people (according to the Foundation experts estimation), at that there is no system of helping people with ALS in the city.

## EXPECTED RESULTS

In 2017, in the framework of operation of the assistance service for people with ALS, nurse/home-based care service should start working in St. Petersburg to carry out regular home-based monitoring, to train family members, to organize hospitalization for PEG tube placement and for solution of emergency situations.

## PROJECT SUMMARY

To organize regular the comprehensive assistance for people with ALS in St. Petersburg and the Leningrad region, to start successful multidisciplinary work of different experts around the family with ALS patient.

To do this, it's necessary to find and train specialists, to prepare a legal base for Service work, to establish regular events for patients, relatives and caregivers (clinics, training, support groups), to rebuild all of the interaction processes of a multidisciplinary team.

It is also necessary to start fundraising for further support of the service and for development of assistance for people with neuromuscular diseases in the Northwestern District of Russian Federation.

## KEY STAGES

2016

**March**

Patients and doctors from St.Petersburg asked to help with the opening of the service

**May**

We carried out the 5-day training of physician Vera Demeshonok

**July**

The first polyclinic reception in St. Petersburg took place

**September**

The first school for in-home care took place  
We started the process of signing the contract

2017

**during the year**

Organization of the service work  
Supervision  
Launching fundraising

# Development and launching of informational portal about ALS — als-info.ru

PROGRAM: "Education and informational materials"

TEAM:

Lev Brylev, Yuliya Dargel, Natalia Semina, external development team, the UX and UI designer, translator, science editor, journalists, cameraman, illustrator, web designer, programmers

## WHAT FOR PROBLEM IS BEING SOLVED

ALS is a rare disease, there is no information about ALS even in the specialized medical sources. At that the information itself about how the disease will progress, what kind of support is needed, and where and in which volume it may be obtained may be already a big help.

## EXPECTED RESULTS

The ability for person to get the information about ALS relevant to his situation quickly, conveniently and in the right amount in Russian in any place of the world, provided that there is an Internet.

## PROJECT SUMMARY

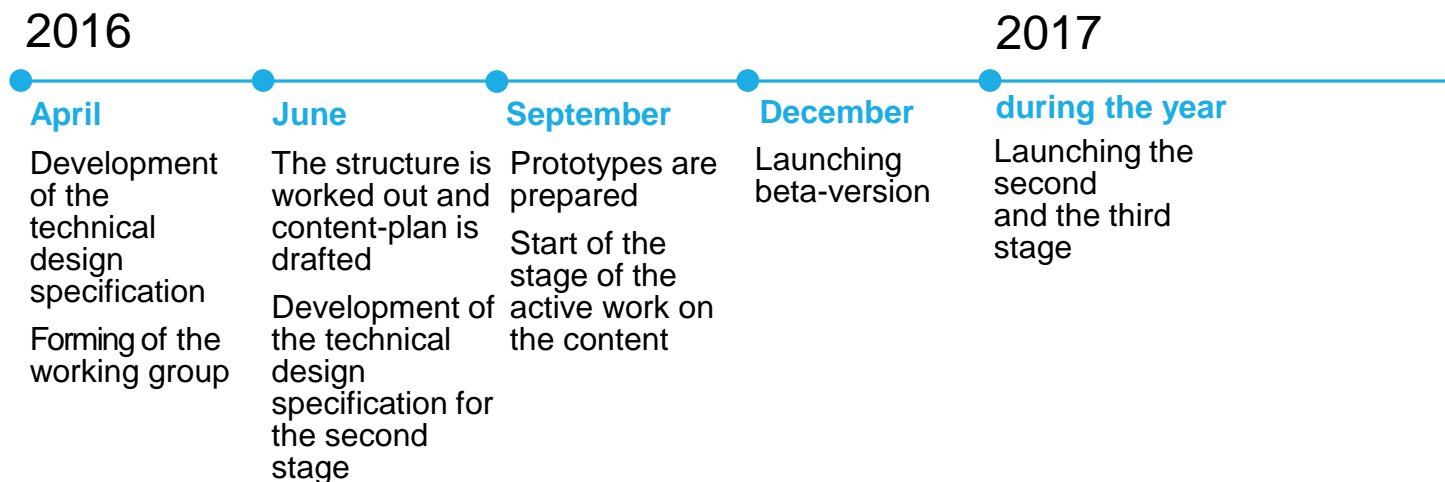
To design the an information portal as a source of reliable information for all categories of people who faced with such a rare and complex disease as amyotrophic lateral sclerosis.

Materials for patients, their families, caregivers, health workers, volunteers and all those who involved in helping people with ALS will be presented on the website.

There will be materials about the disease, diagnostic, complex problems and ways to solve them in different sections. as well as how to organize the life of a person with such a diagnosis to continue just to live, despite the disease.

Information and articles about the disease will influence the change of situation on giving assistance to people with ALS and awareness of authorities about problems.

## KEY STAGES





# Special project — stories of people with ALS

PROGRAMME: "Awareness-raising"

TEAM:

Mariya Ilchenko, Natalia Semina,  
famous journalists and  
photographers

## WHAT FOR PROBLEM IS BEING SOLVED

Only a few people know about the problems of patients with ALS, even experts sometimes do not understand what a disease presents and what the patients and their families have to face.

## EXPECTED RESULTS

Awareness-raising about people with ALS through the creation of vivid human stories written by well-known journalists with involving professional photographers

## PROJECT SUMMARY

To establish a process of regular (one per month) publications about people with ALS; about life, not about the disease.

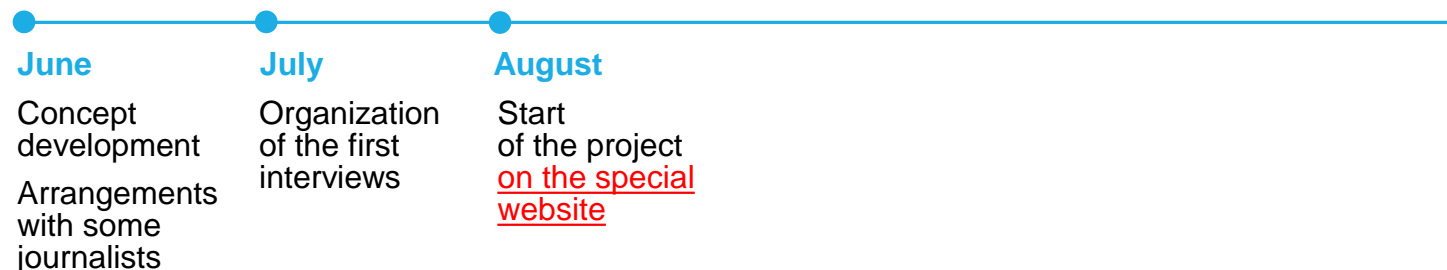
To create a special mini-website, where these stories are published.

To attract the well-known journalists with wide resonance publications to cooperation. Thereby we expand the range of readers due to the media weight of the authors.

To attract the brightest photographers to cooperation to create an additional visual story of our patients.

## KEY STAGES

2016



# Impact of the stress on ALS development

PROGRAM: "Researches"

TEAM:

Lev Brylev, Vera Fominykh, Kirill Gorbachev (physical therapist)

Employees of biochemistry laboratories that analyze samples

## WHAT FOR PROBLEM IS BEING SOLVED

Assessment of the stress impact (with the PEG tube placement as an example) on the course of the disease.

## EXPECTED RESULTS

The hypothesis is that the decrease of stress in the second group leads to that the nervous system in the second group will stay better preserved than in the first one.

Additionally we convert and validate the scale on assessment of cognitive abilities, and also master all the subtleties of the endoscopic PEG tube placement fistula by ALS.

## KEY STAGES

2016

●  
May

Drawing up the protocol

●  
June

Conversion and validation of cognitive impairment scale

●  
July

Beginning of inclusion of the patients

2017

●  
October

Completing of inclusion of the patients

2018

●  
January

Drawing up the protocol

## PROJECT SUMMARY

Many researchers believe that stress can provoke the development or worsening of neurological diseases. However, it's difficult to measure stress in everyday life, because it occurs unexpectedly, there is no doctors around at that moment and the intensity of the stress cannot be estimated.

The PEG tube placement is a stress also (emotional sufferings, pain, short-term lack of oxygen during the procedure). We measure the stress in the first group of patients according to the blood biochemical value (cortisol, glucose) during the PEG tube placement, then we remove the part of the stress effects in the second group of patients (giving them superficial anesthesia for reducing pain and mask ventilation to improve breathing during the procedure) and watch how much is the stress intensive in each of these groups and how is the stress connected with the destruction of the nervous system (nervous system damage by ALS is assessed by the evaluation of scales and measurement of neurofilament, i.e. nerve cells breakdown product in the blood before the procedure and after 3 months).

# Epidemiological study in Moscow

PROGRAM: "Researches"

TEAM:

Lev Brylev,  
Professor Gekht A.B.,  
Professor from Italy Ettore Beghi,  
Anastasia Ataulina,  
as well as and electromyography  
doctor, Moscow neurologists

## WHAT FOR PROBLEM IS BEING SOLVED

The absence of reliable data on the disease and prevalence of ALS in Moscow and Russia.

## EXPECTED RESULTS

We receive numbers on the disease and prevalence of ALS in the Southern district.

In addition, we get the opportunity to evaluate the features of our patient population (risk factors, genetics).

## PROJECT SUMMARY

Currently there is no statistics on the ALS in Russia, the task is to estimate the number of ALS patients in the Southern district of Moscow with a population of 1.7 million people.

It will be possible to rely on these data by assessment of the number of patients throughout Moscow and Russia.

To do this, it's necessary to gather the information about how many of those diagnoses were within the period in the Southern district (in polyclinics and Medical Statistics Bureau), to inform the doctors of the district about which symptoms may be a manifestation exactly of ALS, then to examine all patients with suspected ALS to definitively confirm or refute the diagnosis.

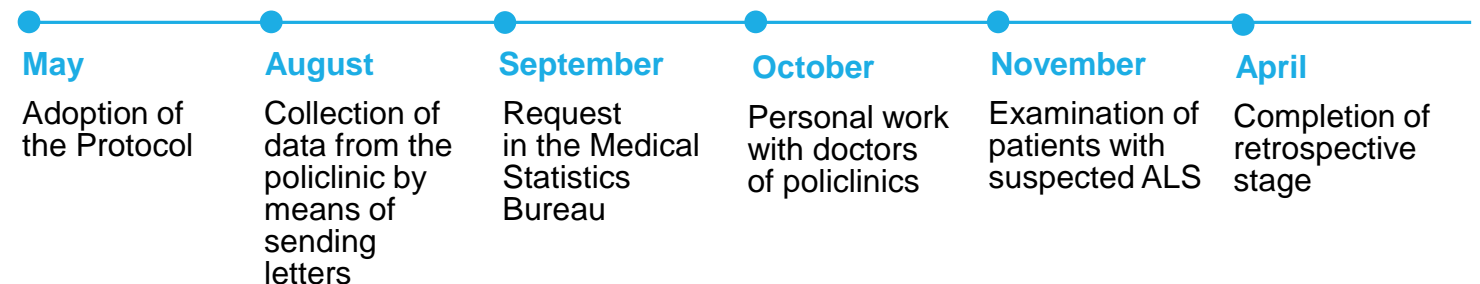
This is the retrospective study.

The prospective study of the prevalence requires additional agreements with the hospital administration, because for do it, we must organize the examination of all patients with suspected ALS of the Southern district by the assignment from clinics.

## KEY STAGES

2016

2017



# ProjectMINE — ALS patients DNA decryption

PROGRAM: "Researches"

TEAM:

Lev Brylev,  
Professor Nikitin S.S.

## WHAT FOR PROBLEM IS BEING SOLVED

The absence of understanding of the ALS causes. We participate in a large international project and look for genetic causes of the disease.

## EXPECTED RESULTS

Identifying of new genes that cause the development of ALS.

In addition, science will get an idea on the prevalence of already known mutations in our population.

## PROJECT SUMMARY

Researchers believe that not all the genes determining the susceptibility to ALS are identified.

ALS patients, together with doctors launched in the Netherlands a large international project on the total decryption of the DNA of patients with ALS from different countries.

Genetic factors may vary in different countries and nations, that's why for completeness the participation as many countries as possible is needed.

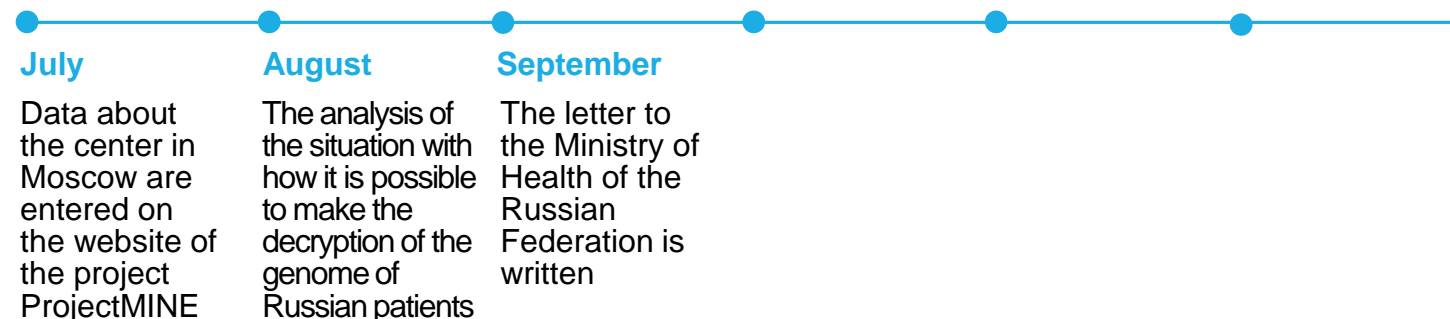
The project may be launched only in case of the obtainment of the export authorization for biological material (DNA) from Russia to Europe, because the export of material is prohibited by the law, and there is no organization in Russia, whose decryption data can be accepted in Europe.

Now we try to obtain such an authorization at the Ministry of Health of the Russian Federation, still we haven't it.

If the authorization will be obtained, it will be necessary to collect analyzes of 200 patients and 100 people without the diagnosis and to send to the Netherlands. Thereafter it will be necessary to find the funds to pay for decryption.

## KEY STAGES

2016



# Breathing exercises in ALS treatment

PROGRAM: "Researches"

TEAM:

Lev Brylev, Timur Ivanov, Olga Davydova (yoga therapist), other physical therapists also may join

## WHAT FOR PROBLEM IS BEING SOLVED

The absence of recommendations for breathing exercises for people with ALS

## EXPECTED RESULTS

We will get effective breathing exercises.

## PROJECT SUMMARY

With the help of the yoga-therapist and foreign physical therapists we compose a set of breathing exercises, which are recommended by physical therapists to ALS patients.

Further, we will recommend this exercises to patients and evaluate how it affects their state of health and respiratory function.

## KEY STAGES

2016

**October**

Preparing a set of exercises

**November**

Writing a research protocol

**December**

Study initiation

2018

**January**

Completion of studies

**March**

Preparation of materials for patients (leaflets, videos)

# Participation in the professional community

PROGRAM: "Researches"

TEAM:

Mariya Ilchenko, Olga Beketova,  
Lev Brylev

## WHAT FOR PROBLEM IS BEING SOLVED

There are problems that are most effectively tackled by the forces of the professional community. Also participation in joint initiatives allows the access to additional resources and best practices.

## EXPECTED RESULTS

We will get an opportunity to act more effectively, systematically and constructively with government officials, to attract additional resources, to learn about the world's best solutions.

## PROJECT SUMMARY

To become a member of the Hospice Care Association to work more effectively in the field of legislative changes.

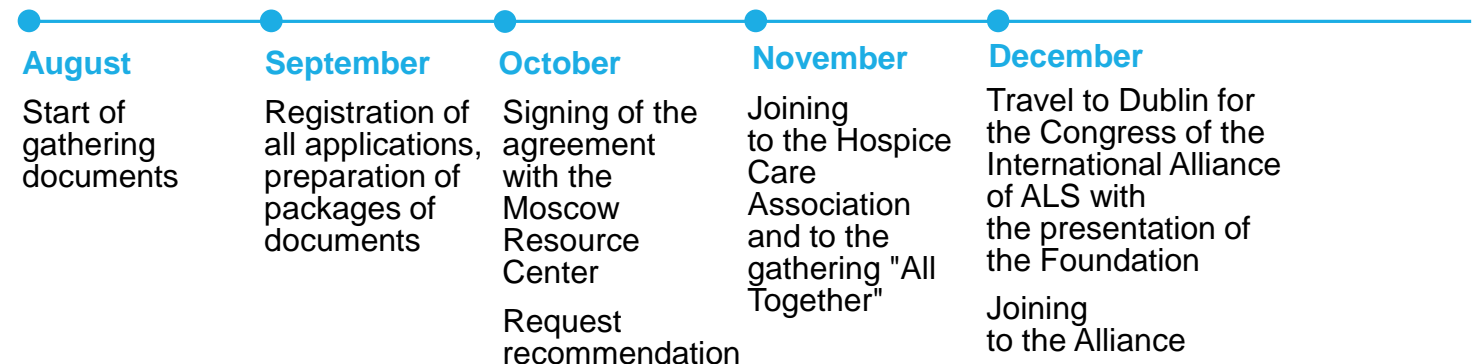
To join the gathering "Vse Vmeste" ("All Together"), for to obtain additional resources and to make friends with colleagues in the nonprofit sector in Russia.

To conclude a contract with the Resource Center of the Moscow Government for to obtain additional resources (coworking, rooms for events organization, photographers, etc.), as well as to take part in and to carry out joint projects with the city authorities.

To join the International Alliance of ALS to get information about the best practices in the world, research news, as well as to improve our reputation in the eyes of the international professional community.

## KEY STAGES

2016



# Development of the music volunteering

PROGRAM: "Quality of Life"

TEAM:

Mariya Ilchenko, Anna Kasyanova, Alisa Apreleva, Anastasia Belyukova and participants of the project [Muzterapevt.ru](http://Muzterapevt.ru)

## WHAT FOR PROBLEM IS BEING SOLVED

ALS is a disease that keeps the whole family on the stretch. Emotional stresses and depression present the almost absolute situation for both the patient and for his family.

## EXPECTED RESULTS

Forming a group of musical volunteers who regularly visit the ALS patients in Moscow.

Opening of the Laboratory of the music volunteering on the base of the Art Library n.a. A.P. Bogolyubov for training of volunteers.

## PROJECT SUMMARY

To provide an opportunity for people with ALS and their families to feel understood, not alone, able to reveal their fears, desires, to live with a normal life through music, family concerts with elements of music therapy and involvement of the patient's himself and his relatives in the musical process.

Families who are attended by musical volunteers will be able to feel various moods through the music, including denial of the disease and that changes are inevitable; also they will express themselves creatively and control the musical meetings, despite the loss of independence of movements.

To prepare the volunteers, it's necessary to perform trainings on elements of music therapy when working with older people with ALS. The training is carried out within the framework of a 3-day schools, organized by the Foundation experts Anastasia Belyukova and Alisa Apreleva. Further, after each family visit, the work on the supervision of volunteers is carried out.

## KEY STAGES

2016

June

Agreed about establishment of a group for volunteers with key partners

Organizators are found

August

The first seminar was carried out

September

Started regular visits to patients  
Organized supervision

November

We started work in palliative department of CCH MP

2017

during the year

Beginning of the work of the Laboratory  
The second workshop for volunteers

# Creating a corporate identity

PROGRAM: Out program, the current activity of the foundation

TEAM:

Natalia Semina, Olga Beketova, designer

## WHAT FOR PROBLEM IS BEING SOLVED

The absence of the guidance for use of the corporate identity hinders the creation of the website als-info.ru.

## EXPECTED RESULTS

Guidance for use of the corporate identity with a detailed description of the foundation identica.

## PROJECT SUMMARY

Guidance for use of the corporate identity is the basic document for work of any organization that helps to create all materials within a single visual approach.

We decided to make a minor update of the logo and create a technical document (guidance), because the foundation works on several projects in which it is critical.

To do this, we have involved a technical designer, whose mission is to collect a single document and to prepare files for basic materials (business cards, forms etc.)

## KEY STAGES

2016

September

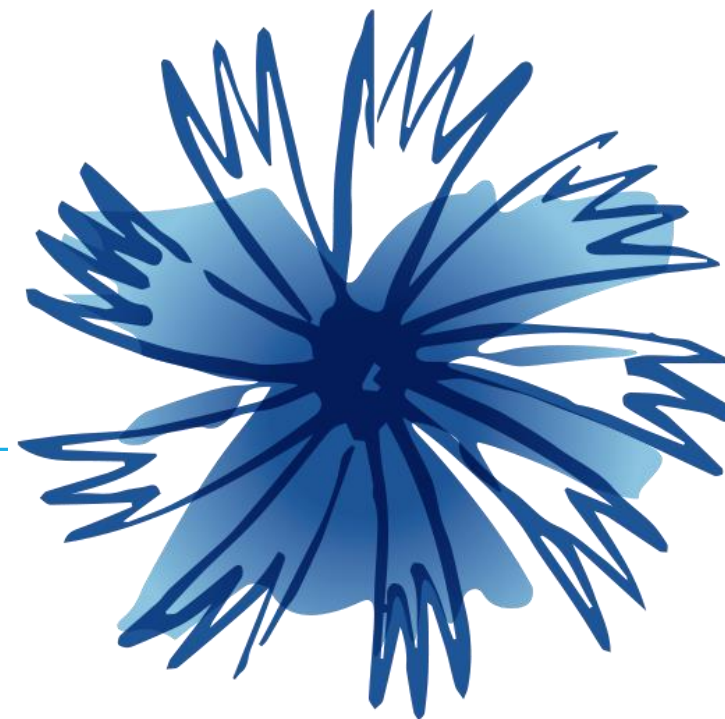
Brief development and searching for the contractor

October

Development and approval of the logo  
Adoption of the basic principles of materials visualization

November

Development of the Guidance (final version)





# Update of the website alsfund.ru

PROGRAM: Out program,  
the current activity of the  
foundation

TEAM:

Natalia Semina, Mariya Ilchenko,  
development team, SEO-support  
team

## WHAT FOR PROBLEM IS BEING SOLVED

The website has uncomfortable interface for collecting donations.

The web site is not in TOP positions of search results.

## EXPECTED RESULTS

Update of the website design.

The introduction of plug-in for easy collection of donations.

Progress in the search results.

## PROJECT SUMMARY

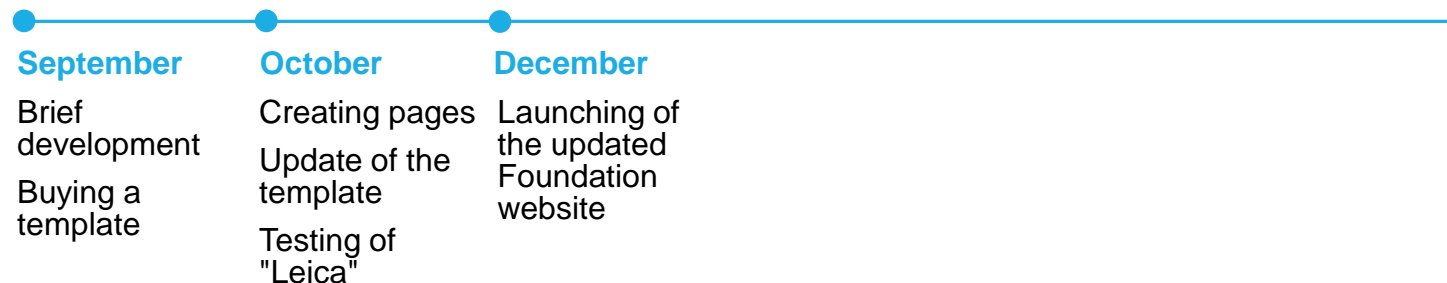
The main task is the introduction of the plug-in "Leica", which allows to accept donations quickly in different ways and to display payments in real time.

This plug-in works only on Wordpress, so the website should be moved to the CMS.

To move the website properly and not to spend money for the design, it's necessary to move the current content to a new template, to implement plug-in "Leica" in parallel.

## KEY STAGES

2016



[WWW.ALSFUND.RU](http://WWW.ALSFUND.RU)  
[WWW.ALS-INFO.RU](http://WWW.ALS-INFO.RU)

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