



Quality of care and compliance in Russian PALS

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GENERAL MEDICAL AND SOCIAL PROBLEMS IN PALS

1) Poor case identification

2) Late diagnosis

3) Poor compliance

4) No optimal international model of medical and social care

5) Problems in scientific studies and clinical trials

EVIDENCE

- 1) **POOR CASE IDENTIFICATION** – less than 50% neurologists do not inform PALS about specialized ALS centers even in the USA (McCluskey, 2004)
- 2) **LATE DIAGNOSIS** – neurologist may be inaccessible for elderly and/or people living far from large cities (Beghi, 2003); there is poor interaction between neuromuscular consultants and neurophysiological laboratories in countries and large cities (Beghi, 2003)
- 3) **POOR COMPLIANCE** - 35% of PALS do not want to prolong life due to FTD, depression or will (Munsat, 1998)

When our Foundation was to be organized by future Trustees, state officials (Academy member, Deputies of Moscow and Moscow District Parliaments) told me that the important intermittent goal of the project is to find out an optimal model of medical and social care for PALS in Russia through study of quality of care and compliance of PALS, and the Foundation has to communicate with its applicants “as a small state communicates with its citizens”

We performed this study in 2010-2013.



President of the Foundation,
Academy member, prof. Vitaly Zverev



Tatyana Potyaeva



Elena Egorova,

The study was performed in Moscow City Ambulatory # 144 (Head of clinic A.Gurin , MD PhD) with support of chief neurologist of North-Eastern Moscow district Anvar Ismailov (in 2010-2013), and in Real Health clinic with private ALS center (in 2013-2014, Head of clinic Ruslana Chub, MD PhD)

We analysed quality of care and compliance in 251 PALS.

Eye-to eye 99 , follow up 16

Documents consultation 152 , follow up 28

Quality criteria – submission to the international standard of ALS management (AAN ALS Practice Parameter), disability registration

Compliance criteria – follow up application each 2-3 months

Compliance (follow up applications)

«Free of charge system”:

Moscow city Ambulatory 144

Primary - 63 , follow up 7 -11%

Russian Charity ALS Found total 16%

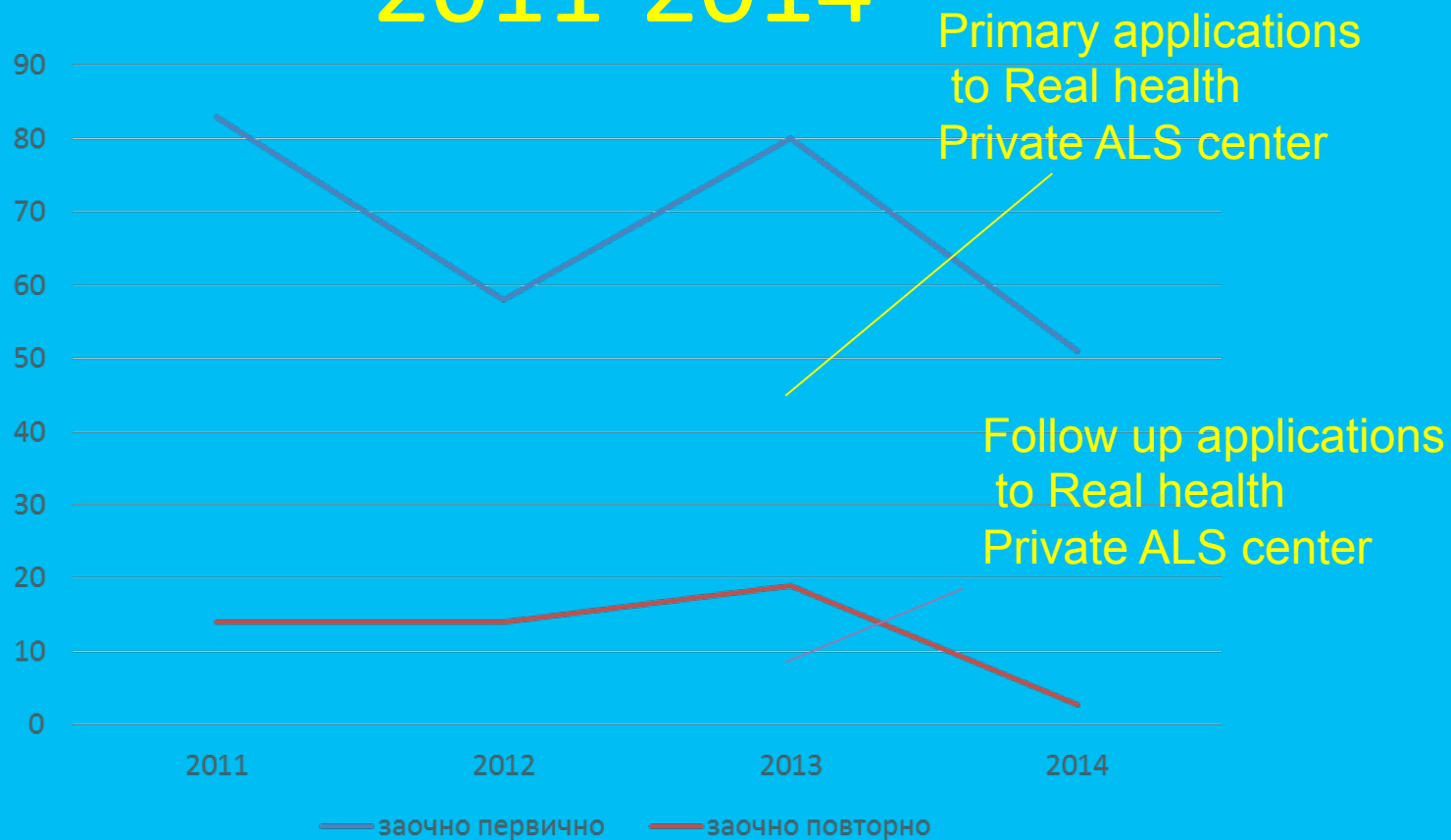
Primary 152 , follow up 28 -18%

«Commercial system, combined system” – private ALS center

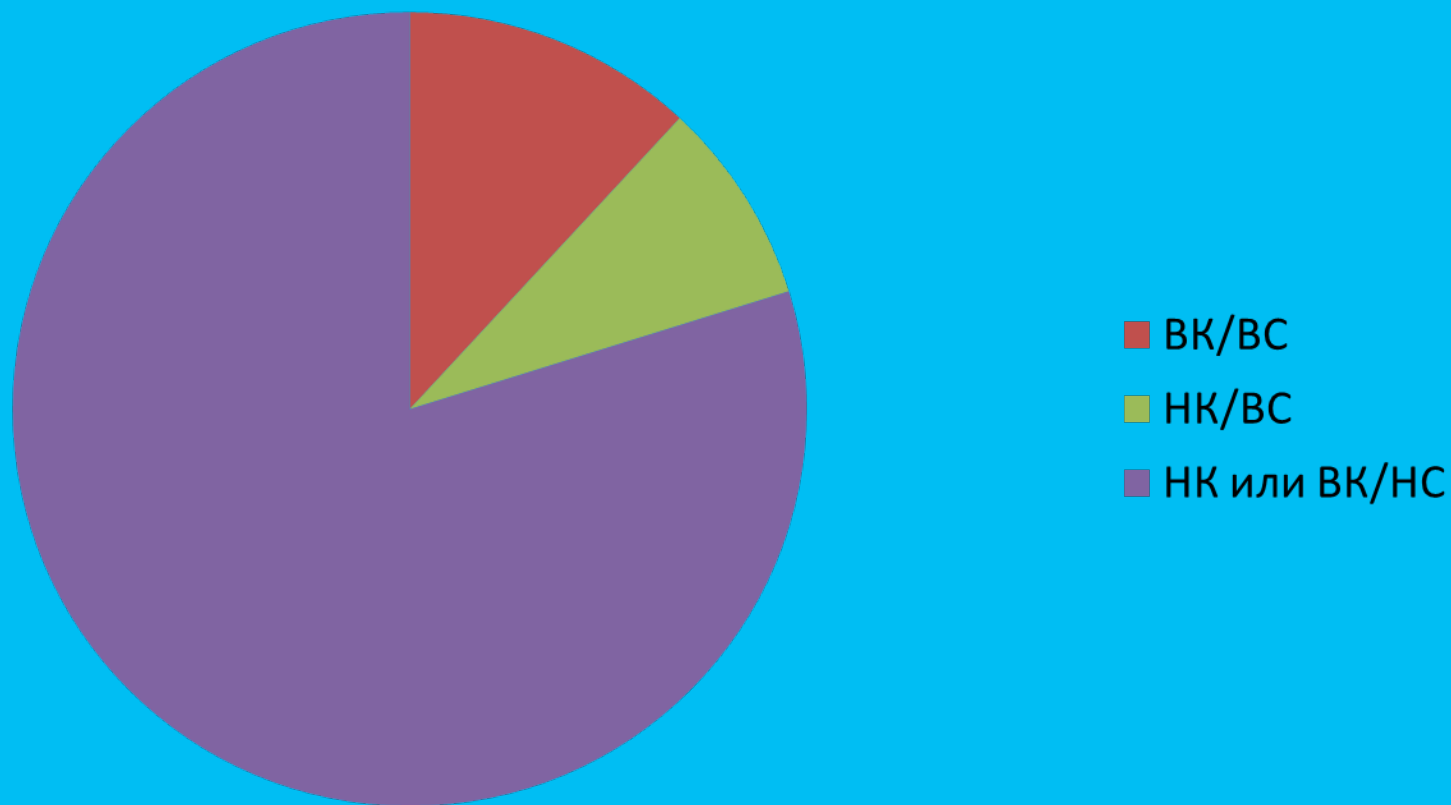
36 primary, follow up 9 – 25%

Applications to Foundation

2011-2014



The study encompassed 4,7% of all Russian PALS

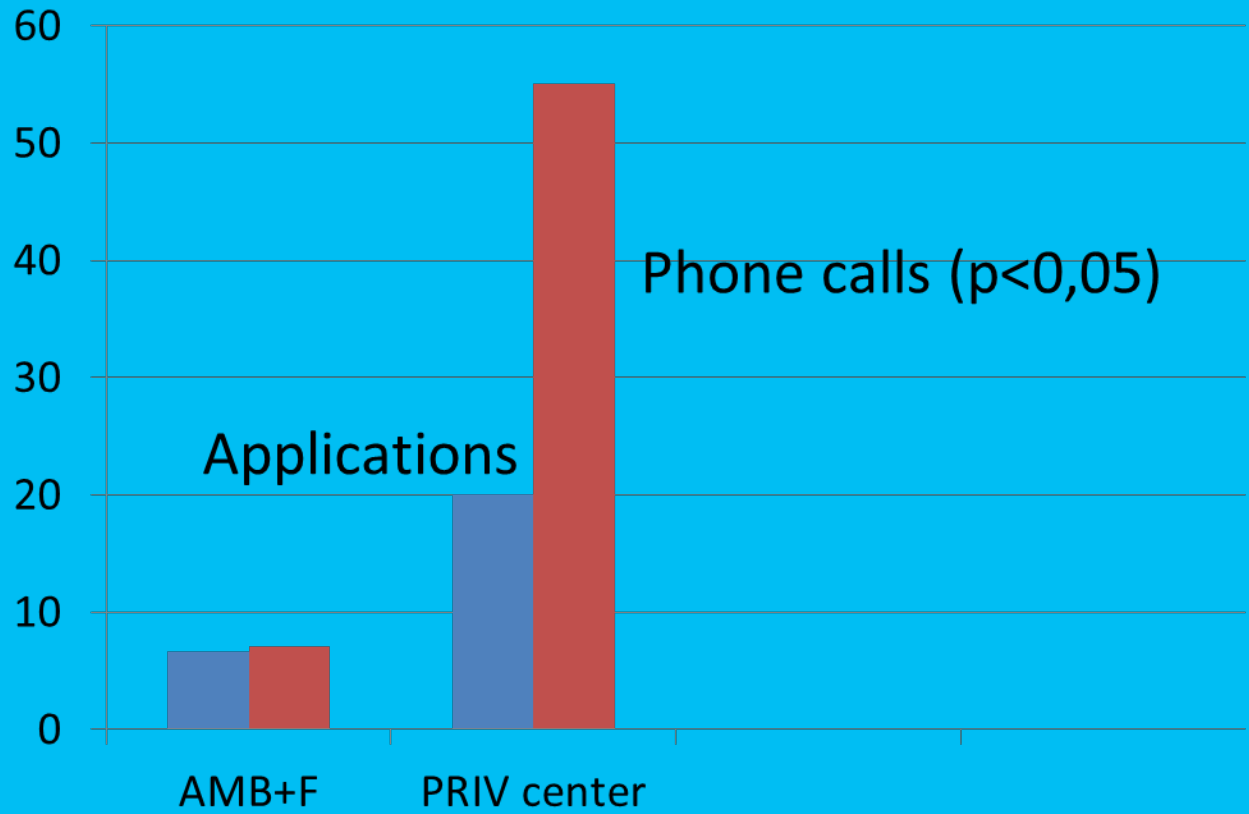


High (or low) quality and low compliance – 79%

Low quality and high compliance -8,3%

High quality and compliance – 11,9% (30 PALS from the project)

Follow up applications + phone calls in Ambulatory, Foundation and ALS center





«Positive», «neutral» and «negative» events with PALS in Russia

NEGATIVE EVENTS (< 12%)

1-STEROIDS, 2- NO NEUROLOGICAL STATUS IN DISCHARGE DOCUMENT, 3- CONSEQUENCE OF DIAGNOSIS, 4- INTRAMUSCULAR INJECTIONS IN ATROPHIC MUSCLES, 5- NO NEEDLE EMG, SODIUM IV TO HYPONATREMIC PALS WITH DYSPHAGIA

NEUTRAL EVENTS

6- CORRECT DIAGNOSIS, 7 – NEEDLE EMG, 8- VITAMINES AND PHYSIOTHERAPY (95%)

POSITIVE EVENTS

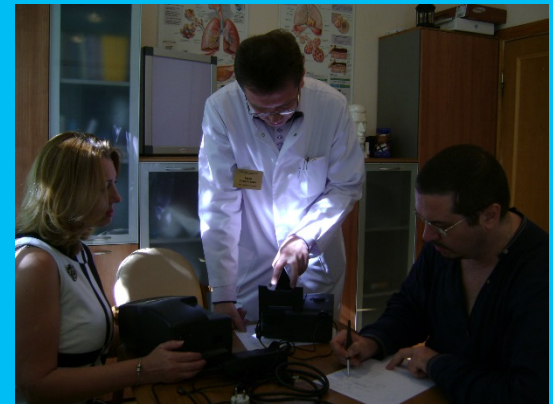
Info or implementation of: 9- PEG, 10- RILUZOL, 11-NIPPV, 12- TRACHEOSTOMY, 13- INVASIVE VENTILATION (< 7%)

CONCLUSIONS

- 1) Organization of State ALS center in Moscow is not feasible due to low compliance
- 2) The most effective system of medical and social care in PALS is a DUALISTIC COMBINED SYSTEM in which services are combined made via insurance, commercial, charity, state social care system with different level of accessibility and different ways of interaction between those who provide and those who consume services (PRIVATE CENTER WITH CHARITY LICENSE + CHARITY FOUNDATION+ EDUCATION IN GETTING STATE SERVICES)
- 3) PALS should be supported by family, charity foundation and the state
- 4) The Foundation should give charity aids (equipment, money) only to those PALS who wants to be followed up

New equipment 13-2014

- In 2013 Savely Baschinsky, Presidium member, purchased Tobbi communicator, and in 2013 – 4 NIPPV, certified ALS neurologist Liya Klimova MD PhD (Novosibirsk) got 1 NIPPV as a present.
- The Foundation gave a device to Kozhevnikov Neurological clinic in Moscow, to patient in Vladivostok, to Roman Kostyuk from Kharkov (Ukrain), 2 devices for Novosibirsk



Cooperation with Ukrain and Belarus



Yulia Rushkevich MD PhD in Minsk
-negotiations with Neurology and
Neurosurgery Institute, we are planning
To open office in Minsk, Ice Bucket gave
55 billion Belarus roubles to the Institute



Roman Kostyuk (PALS from Kharkov, Ukrain)
got our NIPPV,
organized an active group and
registered Ukrain Charity ALS
Foundation after our consultation

ICE BUCKET CHALLENGE

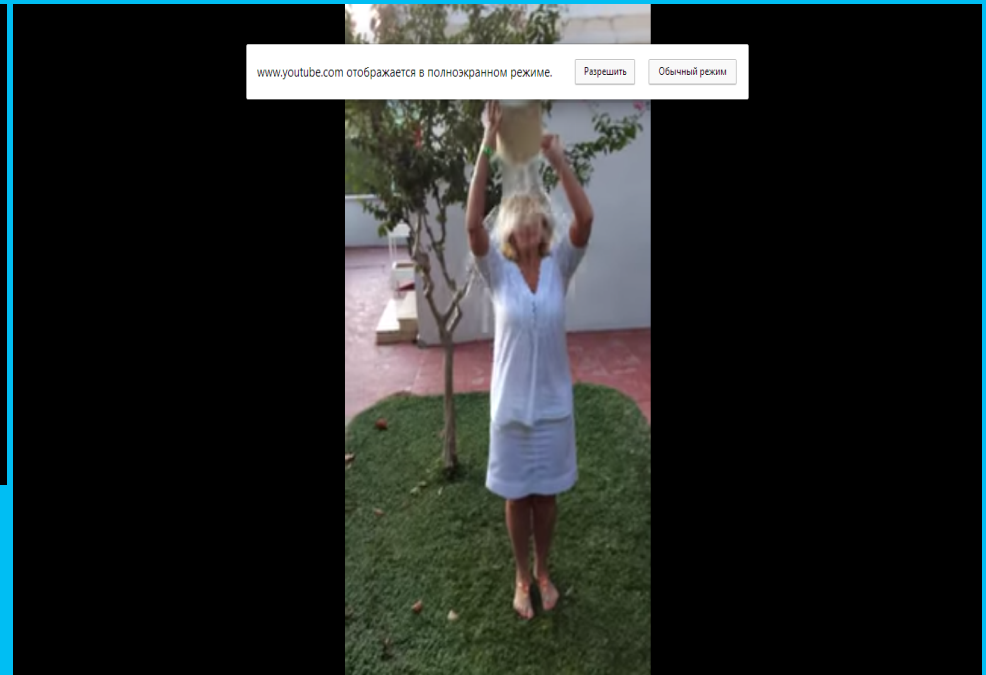
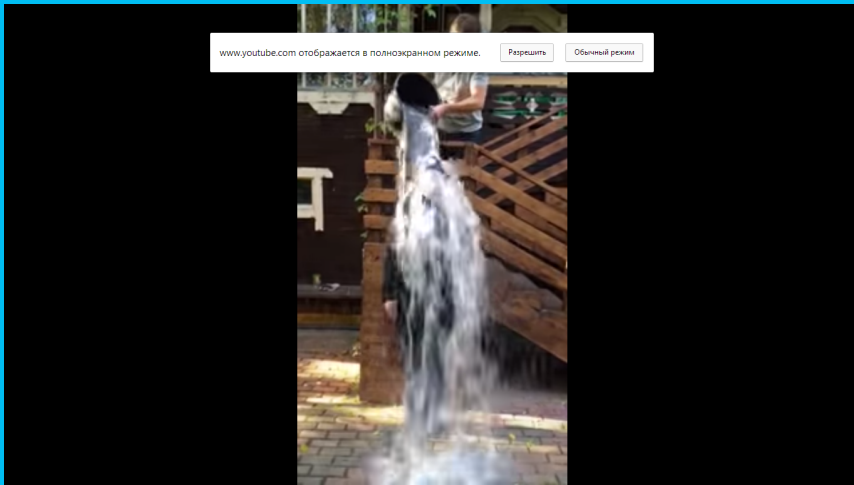
Donation in different countries

Russia – 8000 USD

Argentina – 100 000 USD

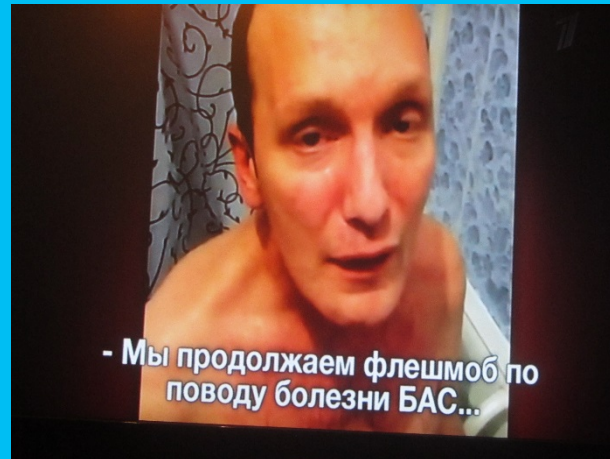
USA – 100 000 000 USD

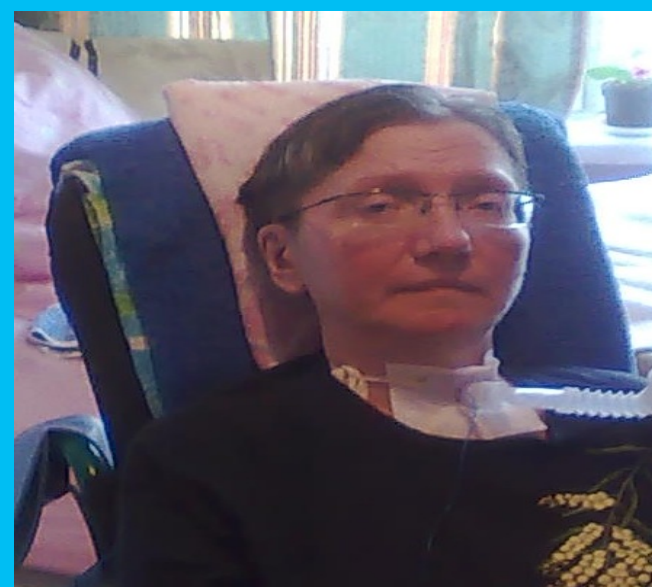
Press secretary of Putin said about Ice Bucket:
«We have much more important affairs to do»



Liya Klimova and Gleb Levitsky, as well as a famous actor Mikhail Boyarsky who donated to our Foundation, partook in Ice Bucket, and Liya Klimova became Deputy Director of Foundation in Siberia (office in Novosibirsk)

Popular TV program «Let Them Say» 2011 and 2014 – from separate destinies to complex highlighting ALS problem





In 2006 - 2014 Russian Charity ALS Foundation gave NIPPV, invasive ventilation and communicator to 18 families, adaptive equipment and medicines – to dozens of PALS all over Russia

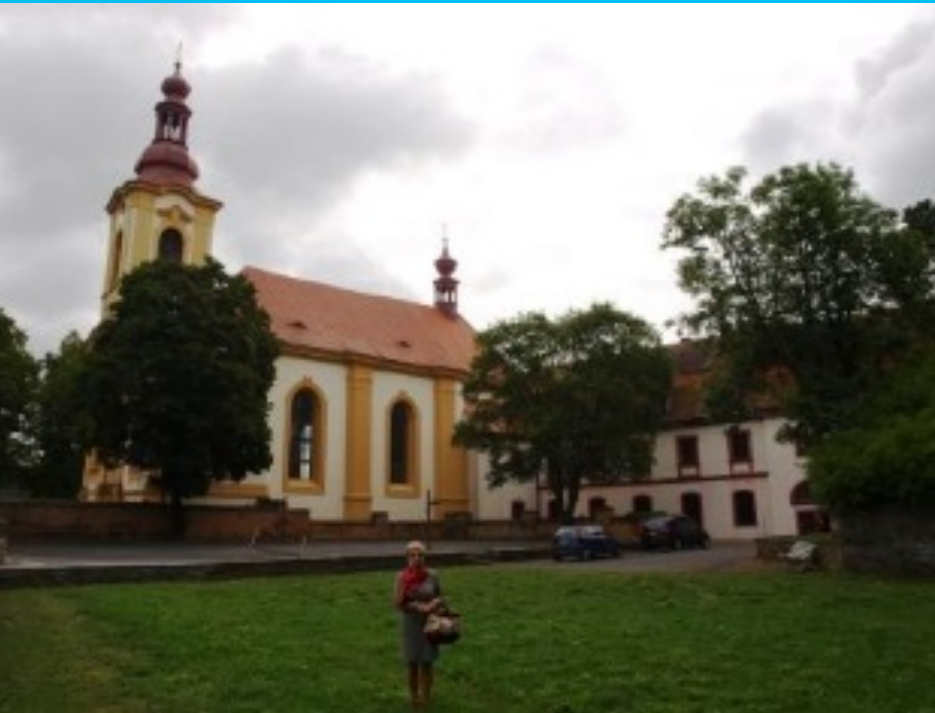
Foundation plans for 2014-16 (1)

- 1) Interconnections with new sponsors and partners
(Alexander Nevsky Foundation in St Petes, Expo Bank, others)
- 2) Commercial projects that fundraise to Foundation (Real health, Retirement Home in Czech Republic, education of personal assistants of PALS, book «Phylosophy of Fight with ALS», fiction movie with mentioning of ALS- script given to Nikita Mikhalkov)
- 3) Expansion in geography due to low donation in Russia :
offices in Novosibirsk, St Petersburg in Russia, in Minsk, Belarus, abroad - Luxembourg, Czech Republic, Norway, Sweden (high personal income, high donation level, small quantity of PALS but no intrinsic ALS clinical school and \or several problems in medical and social care for PALS due to conservatism in medical and social systems)

Foundation plans for 2014-16 (2)

- 4) Expansion of donation boxes and electronic donation systems
- 5) New office in the center of Moscow
- 6) Nosological expansion – aids for children with neuromuscular diseases
- 7) Probably international juridical support of PALS in case foreign grants are available
- 8) Continuation of scientific studies
- 9) Further purchase of NIPPV/invasive ventilation devices, communicators (Russian, Swedish, Spanish), enteral feeding pumps and formulas

Retirement home in Chechz Republic



Luxembourg - Viaduc



PHYLOSOPHY OF FIGHT WITH ALS(1)



ALS



PLS



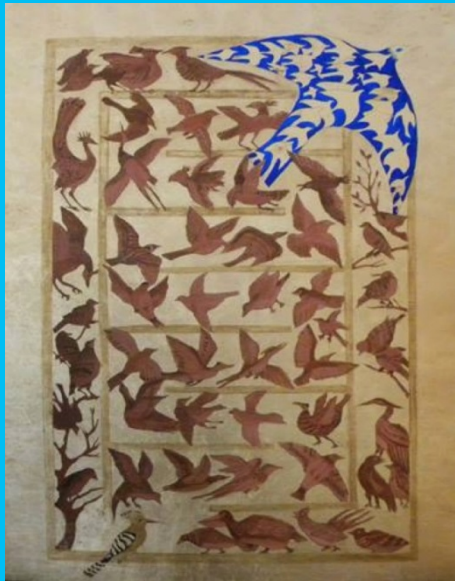
PMA



PBS, PBP

WE FIGHT MONSTERS (by Valery Shechkin)

PHYLOSOPHY OF FIGHT WITH ALS(2)



SIMURG BIRD



HARVESTER OF SORROW



LADY SOCIETAIRE



SOLDIER OF FORTUNE

Phylosophy of fight with ALS(3)

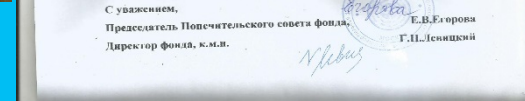
We plan to issue the bilingual book (Rus/Eng) with life descriptions of PALS and ALS doctors worldwide

Please send stories and photos alsrus@gmail.com

Savely Baschinsky
and Gleb Levistky



The 3rd certification course on ALS for neurologist and the 1st for personal assistants (2014)



FULL MEMBERSHIP IN THE INTERNATIONAL ALLIANCE SINCE 2012



СПАСИБО! Thanks!



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