



Blind Children's Center



"...to help blind children,
to equip their parents,
to bring light to their lives"



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1. INTRODUCTION

"Light Of Life" (LOL) is a Ukrainian charitable organization. Founded by Christians, it is dedicated to serve people in Ukraine and other countries of the former USSR through the social and publishing projects in which it is currently involved.

One of the main focuses of LOL activities is "Light Of Life" Blind Children's Center, which started in November 2000. The LOL Center works with children who have severe visual disabilities and with their parents by

- providing the special training programs for children from birth to 6 years old,
- publishing a variety of materials on different aspects of raising blind children,
- organizing parent support groups in an environment where literally no special assistance

is available for them and a society which seems to be unable to help them with their problems.

2. LETTER

Dear Friends,

The four years, since we felt that the Lord called us to start a ministry for blind children and their parents, have passed quickly. From the very beginning we realized that, by personal challenges that God allowed in our lives, He wanted to make a difference in the world we live in — around us and through us.

It is always difficult to call the appearance of a blind child in a family God's blessing. But within four short years we have seen how, through our young son Pasha (who due to disease lost his sight short after his birth and underwent two very complicated surgeries in the US), the Lord is accomplishing His own plan. Today the ministry, which has grown out of our family's personal problems, embraces many families. The activities of the "Light Of Life" Blind Children's Center are really able to help children with visual disabilities and (which is even more important) give hope to the parents. After facing the sad realities of raising a blind child in post-USSR countries, parents often consider their situation as a lifetime tragedy, everlasting curse, and an end of times. What a blessing is to see how the light of life and the joy of parenthood return to them, how they break through severe depression and restore their abilities to be happy again, to enjoy their family relations, and to be proud of their child's successes! All this brings real joy to our hearts. You can imagine that, shortly after the time that the parents receive the bad news from the doctors, they need Christian counseling just to survive the shock. These are the moments when they so much need somebody to share



the light of Gospel with them. And we are happy to be there for this purpose, too.

We know that many of you, who will be reading this report, were and are personally involved in this ministry. We would like to take this opportunity to thank you so much for your love, your prayers, and your help. We thank the Lord for those of you who supported our mission financially — 100 percent of the funds supporting our ministry to date come from individual donors.

On the following pages, we will share with you the results of the LOL Center activities within the past four years — what we gained and where we fell short, what our objectives are today and how we see the future of this ministry. We would like to thank you again for your efforts and ask you to keep us in your prayers.

Sincerely,

Alex and Oksana Yefetov

3. FACING THE REALITIES

Statistics show that in Ukraine by year 2002 there were about 65,000 people who are legally blind (UkrStat/Ukrainian Society Of Blind data). The number of blind children from birth to 6 years of age among them is about 1,000 (estimates based on European Blind Union and Lighthouse International data). Totally in the countries of former USSR today there are about 4-5 thousands of such children.

More detailed calculations of the number of children with visual impairments in Ukraine are very contradictory. There is no nationwide registration of these children. The ophthalmologists in district and regional children clinics do not have records of such children. Often they do not know all blind children in their district because many of these children simply do not need an ophthalmologist.

Amazingly, there is still no institution/organization other than the LOL Center dealing with children with severe visual disabilities under the age of 7 in Ukraine. Few kindergartens, located mostly in Kyiv and big cities, work with visually impaired children; several boarding schools for the blind are located around the country. When Oksana came back to Ukraine after Pasha's first surgery, she called the National Ministry For Public Education trying to find out the situation with preschool institutions and/or programs available for blind children. Their answer was quite typical: "Nothing...Do they need anything?" — "Well, but for the sighted children you've got kindergartens, music and dancing classes, art studios, ...?!" — "Yes... You are right. But we can offer only a rehabilitation program... for you, Madam. That's it."

Parents of blind children visiting the LOL Center have shared with us what kind of assistance they received. One mom from Smela (a small town not far from Kiev) says that in the course of the "rehabilitation" program the psychologist absolutely seriously suggested that she should... abandon her blind child in order to preserve the family. "Sooner or later this man will abandon you," said the professional psychologist sitting in front of her astonished husband.—"You should send your child to the orphanage before it is too late... It will be good for your child, too. The food is very good there..." Similar "counseling" was recently given to another mother at one of the national rehabilitation centers in Kiev.

Many stories like this could be reported, but the general idea is clear: In Ukraine today there is absolutely nothing available for development and education of young blind children. Moreover, after our 3 years of working with blind children, we realize that many of them have developed neurological and psychological problems by the age of 5, none of which were caused directly by their blindness, but rather by the social environment they live in because of their blindness.



Ukraine inherited from the Soviet regime an attitude towards the blind as mentally retarded semi-humans. They used to live in small ghettos in big cities and work at special factories doing primitive operations like assembling electric wall outlets and switches. Those very few exceptions when blind people became teachers, lawyers, and scientists just proved the general rule: Most could not fit into society.

This established a public opinion about blind people, which is now a factor of tremendous extra pressure on parents who just found out that their child is blind... No wonder the family often could not survive the shock and suffered many sad consequences. Statistics show that in about 70 percent of such families the husband either starts drinking or abandons the family within the first six months. In both cases the social status of such a family quickly falls below the poverty level and the parents become unable to raise their blind child adequately. For these and other reasons, they try to hide their blind child from people's eyes, and sometimes sending the child to their relatives in rural areas.

In starting the LOL ministry, we realized that first and foremost our work should be focused on breaking the existing stereotypes.

4. THE LOL CENTER STARTS

Although the LOL Center was registered in September 2001, the actual work began in Fall of 2000. While in the US, we were able to meet various vision specialists, parents of blind children, and people from the National Federation For The Blind (NFB). They helped us tremendously in collect-



ing various useful information and materials on different aspects of raising blind children. We saw how valuable this information was for us as parents of a blind child and how unique it is for our country.

The strategic directions of our activities were set as follows:

1. Creating a database of the blind children throughout Ukraine — finding their names, addresses, ages, diagnoses, social situation in their families, special needs, etc.
2. Translating, adopting to the cultural realities of the CIS countries and publishing various materials that can help parents of visually impaired children.



3. Developing and providing the special training programs for blind children of ages 0-6 and teaching parents the special techniques they need in raising blind children.

4. Organizing regular meetings of parents of blind children for idea/experience exchange and training.

5. Developing working relations with different institutions working with blind children.

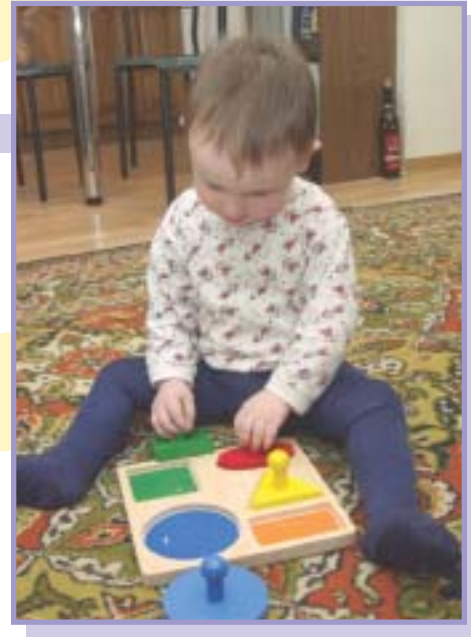
6. Promoting the information about the LOL Center and its activities through various channels, including a community type web site of the project.

The following pages describe the progress we made in these endeavors.



5. PROGRESS TO DATE

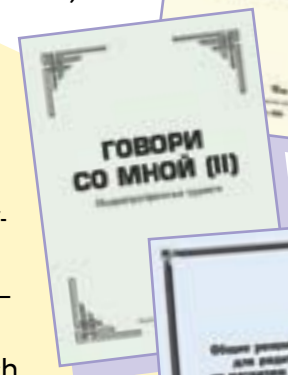
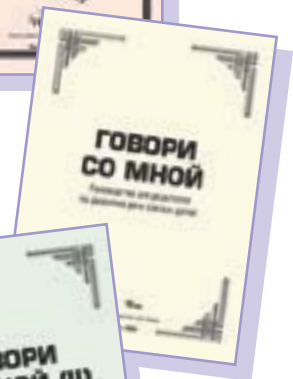
The Team. Initially the LOL Center's team consisted only of Oksana and Alex Yefetov. In winter 2001 it grew by half when Svyeta Vanyuk joined us. Today she is working full time as a preschool teacher and mobility specialist making great progress in adopting the known techniques and developing original ones for working with blind children. Besides these three, today's LOL team includes a translator, a designer and an accounting person — all work on a contract basis. Other than Alex and Oksana, there are no volunteers. As it was from the very beginning, the LOL is headquartered in the Yefetov's apartment.



Database of Blind Children. The LOL created a database of blind children between 0 and 6 (the ages we are most interested in). We think this list is far from exhaustive. It is very difficult to find these children, because sometimes there is no direct information on them; and, even if we can locate them, their parents are not always cooperative. Many of them (especially at the very beginning) are totally focused on a surgical solution. They do not want to even hear about any counseling or special training, when they still have some faint hope that "everything is going to be fixed". Due to the reasons we described above, parents often are not anxious to acquire any special skills and knowledge in raising blind children.. They are just focused on meeting the physical needs of their child and set aside all other aspects of their parenthood. Today we work with 34 families who have blind children (33 are in Ukraine, 1 in Belarus).

Publishing Activities. Today the LOL Center has all the facilities necessary for producing the full cycle of prepress operations for the materials it publishes. Since the Fall of 2001, the LOL Center translated, culturally adopted, and published 13 manuals describing various aspects of raising blind children (e.g., orientation and mobility, eating, communication skills, and socialization) with an overall volume of about 260 pages. All published materials are sent free of charge to the parents we work with at the LOL Center.

Training Programs. Based on various materials developed by NFB and other US and European organizations working with blind children, the LOL Center has developed special training programs adapted to the cultural and social realities of the countries of the former USSR. The lesson plans focus on the main aspects of raising and educating blind children — developing mobility and motor skills; teaching orientation; eating skills; speech; memory and mental development; socialization; etc. The approach that these programs offer differs dramatically from the usual practices used by local institutions and, although well known and widely used in western countries,





is considered unique in Ukraine.

The LOL Center's specialist regularly visits blind children at their homes (usually two times a week) and carries out individual training sessions that flexibly meet the specific needs and age of each child. Today, because we have only one prepared specialist capable of conducting this kind of training, we can reach only the blind children living in Kiev city. We work most actively with 17 children aged from 0.5 to 6 years. The training sessions have twofold purposes — to actually help the children in their development and to teach their parents how to supportively raise their children. They all include homework assignments and extra training to be carried out by the parents themselves.



Parents' Support Groups. Two times a month we organize meetings with parents (mostly mothers) of the blind children we actively work with at the LOL Center. At the meetings we usually present a prepared topic of common interest, have an exchange of opinions, Q&A session, and discuss the problems parents had during the past month. Parents living in regions outside of Kyiv sometimes attend these meetings, but more often they prefer to just visit Alex and Oksana to share their news, discuss their problems, and get LOL updates.

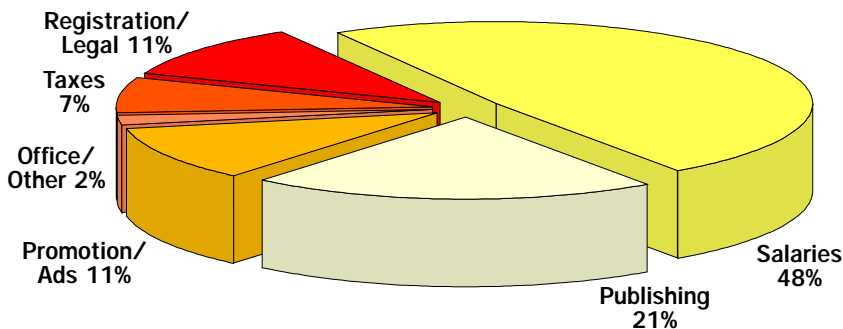


Promotion of Services. The Yefetov's son Pasha (age 4.5, with retinal detachment in both eyes due to ROP stage V disease) has become the most convincing promotional tool of the LOL Center. Because all the new training programs and techniques the Center developed were adapted and tested on him first, today Pasha is a walking result of the approach and methods promoted by our Center, combined with parent's love and care. Pasha indeed is very different from the common image of a blind child in Ukraine. In many aspects Pasha is much better developed than his sighted friends of the same age. He lives the life of a happy young boy and has many

friends. When we start working with a new family, first of all we try to invite them to visit our office and see Pasha. Often this has a tremendous hope-giving and "eye-opening" effect on parents. They start to realize that nothing fatal has happened in their lives, and the joy of parenthood can still be a reality for them, too.

Of course, Pasha is not the only way of making our work known. The LOL Center has good

USE OF FUNDS



This diagram shows how the funds were used in operations of LOL Center in 2001-2004

connections with many institutions around the country that deal with blind children — children's hospitals, schools for the blind, public organizations of people with disabilities, Christian organizations, and churches. A booklet describing LOL activities was published and distributed among district children's clinics and children's ophthalmologists in big cities around Ukraine. A full-page advertisement of LOL appeared in each issue of "Christianity" — a nondenominational Christian magazine with a run of 10,000 copies distributed around Ukraine as well as in other countries of the former USSR. The LOL staff participates in various exhibitions, conferences, seminars, and public events on topics related to our interests.



6. LESSONS LEARNED

Our three years of experience in running the LOL Center has given us a much deeper understanding of the situation with blind children in Ukraine. Today we realize that there are several issues that should be taken into account when we look toward the future of this ministry:

1. The most striking lesson we learned: Parents are generally not very enthusiastic about being involved in LOL activities. The initial thrill Alex and Oksana felt when they started the LOL Center — sharing with parents the "good news" about ways of raising their blind children, making disciples among parents, and spreading through them the "good news" to the further regions of Ukraine — soon cooled down. Facing the realities described above (Chapter 3), we realized that some parents of blind children have a growing temptation in their hearts to just cross this child out of their lives and to get rid of this burden. They are often skeptical about what they hear at the LOL Center, simply because it is a convincing argument against such plans. Many parents of blind children live with a more or less hidden feeling that society and the people around them owe something to them because they are less fortunate than others. This idea, being fairly common in a society where everyone tries to get to the state of maximum personal comfort, makes them gladly accept LOL services with minimum participation and no feedback. This state of mind requires some time for recovery.

2. The ministry cannot become self-supportive in the near future. Due to the social realities described above, parents whose children get help from the Center cannot provide adequate financial support of its' activities.
3. The staff of LOL specialists (as well as regional representatives) cannot be formed from mothers of blind children who have acquired some of the necessary skills and want to help others the way they were helped. Therefore, we plan to attract students of pedagogical colleges and universities, preschool teachers, or Christians who want to become the part of this ministry.

Remembering that our primary goal is the future of blind children, we keep this in mind and continue our work.

7. CONSULTANTS AND ADVISORS

The LOL Center currently works with the following individuals and institutions around the country:

- Elena Lepekhova, Prof., MD, Chief Pediatric Ophthalmologist of Kyiv city and region
- Tatyana Orlova, MD, Head of the Prenatal Pediatrics Department of "Okhmatdet" hospital
- National Institute For Eye Microsurgery
- "Okhmatdet" Central National Children's Hospital
- Ukrainian Association of Blind Lawyers



Spreading the good news: the ads of the LOL Center and the scope of services it provides in booklets (left) and in Christian media (above)

8. PARENTS SPEAK (TESTIMONIALS)

We asked some of the parents we work with to share what they think about the work of the LOL Center: how it helps them in raising their children and how their lives changed after they started working with the LOL Center. Here is what they say:



Tanya Pavlichenko

Communication with people who faced exactly the same problems as I did gave me so much assurance that everything could be changed for the better, and that there is no need to despair. LOL helped our children learn a lot about the world around them... — Tanya Pavlichenko, the mom of blind twins (3)

The LOL Center helped me to realize that my child has every opportunity to have an abundant and happy life. I learned peculiarities of the development and perception of the world my child has. I learned how to be filled with joy and happiness from communications with him. The LOL Center helps my child to fully adapt to life, to learn how to fully use his abilities. He enjoys studying and getting new skills. I am so happy that there is such an organization. — Natasha Yankovskaya, mom of a blind boy (1.5)

I am so grateful to people working at the LOL Center for their tremendous support. Before getting to know them we were "isolated" from society. We could not find the answers to the tough questions like: What do we do with our child? How do we raise her? The real help in raising and development of our child we got only after we came to the LOL Center. The knowledge we receive is also very important as it gives a real hope for the future and answers many questions. Meetings with parents of similar children, exchange of experiences, discussion of the problems, and mutually finding the right solutions became possible only at the LOL



Svetlana Vovk

Center. After they started working with my daughter, she became more quiet, attentive, sociable. I see her really developing — and this brings real joy... — Svetlana Vovk, mom of a blind girl (5)



Olya Kalyuk

The literature the LOL Center gives us is read by the whole family — Thank you! We are now optimistic, we are learning how to raise our child, and we no longer see our situation as a tragedy. — Olya Kalyuk, mom of a blind daughter (3)

9. PLANS FOR THE FUTURE

We realized recently that the LOL ministry needs qualitative changes. The ministry has become much better known. The number of families we are working with has grown by 20 within last 12 months. Having just one training specialist is not sufficient for the project. The need for some growth is obvious. So, within the next few years we plan to:



1. Continue the search for new children around the country. So far we have been able to completely cover just the Kiev city area. The most effective way of delivering information about us to parents has been through the local district ophthalmologists, whose offices we visited personally. Today we seek a supportive letter from the Chief Pediatric Ophthalmologist of Ukraine to arrange a direct mail shipment to all pediatric ophthalmologists in the country. There are also plans to get some church unions in regions outside Kiev involved in the ministry.

2. Expand staff training. In the near future the LOL Center will need to prepare at least 2 specialists (one from Kiev and at least one from another big city) to provide training sessions for blind children and their parents. We plan to organize a training session for 2-3 persons at similar centers in the US (i.e., the Blind Children's Center in Los Angeles, CA)



3. Develop a program for elementary school. The existing schools for the blind in Ukraine offer very old-fashioned programs, which have remained practically unchanged from Soviet times. They lack not only the widely adopted integrating approach, but sometimes even common sense. Example: school students do not use white canes for independent travel because they are ashamed to do so in public! Also, the white cane technique is introduced to them at age

13 (in the US — at age 2), when they have already become accustomed to living without it. There is great need for elementary school preparation and for appropriate preschool education.

4. Continue the meetings of parents' support groups (currently held biweekly), with more focus on parent's encouragement and the progress they make in achieving special skills.
5. Start publishing a newsletter with the latest updates, useful facts, and materials (partially based on translations of NFB periodicals "Future Reflections" and "Braille Monitor").
6. Develop a web site of the project. We plan to make it work more as a community portal with a variety of services including an online purchase of special equipment/products for the visually impaired.
7. Continue and develop the other activities the LOL Center is currently involved in.



10. WANT MORE INFORMATION?...

If you are interested in knowing more about Light Of Life Ministry, receiving our regular information updates, or helping us in any way, please contact us...:

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