

Microphthalmia in Russian Orphanages

ABSTRACT: *Western media have depicted Russian and Eastern European orphanages (Romania in particular) as horrible institutions bursting with thousands of abused, neglected and unwanted children. Many of these children have disabilities, including microphthalmia.*

Given an opportunity to travel to Russia to work with orphans suffering from microphthalmia, anophthalmia and other congenital anomalies, the author was surprised by the conditions he encountered. For this article, the author wishes to share his experience in working on these special cases and the impact it has had on both his life and the children's lives.

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Since the collapse of Soviet rule in 1991, Russian orphanages have been filled with abandoned children, casualties of the turbulent social and economic transition that Russia is experiencing. The orphans' families are often poor, jobless or ill. As many as 95 percent of abandoned children have at least one living parent. According to records published by UNICEF in 1997, there were 611,034 Russian children "without parental care." Of these, 337,527 were housed in baby houses, children's homes and homes for children with disabilities.

A child who is born even with a slight physical disability, such as microphthalmia, cleft palate, or clubfoot faces terrible prospects if he or she is abandoned at birth. All orphans in Russia are herded through a maze of state structures operated by various government agencies, which compete for limited state funds and overlap in their mandates for specific categories of orphans and children with disabilities.

The Russian Ministry of Health is charged with the care of abandoned infants from birth through age four. These children spend their first three to four years in a baby house. Later they are moved to institutions under the control of the Ministry of Education or the Ministry of Labor and Social Development. The children under the Ministry of Education are classified into two groups. The first is considered to have no disabilities; the second group contains children diagnosed with disabilities. All of the microphthalmic children are classified as slightly disabled and officially termed "debil."

When a child is born at a Russian state-run hospital or maternity ward, the baby is left in the hands of the staff, who observe the child, giving him or her various medical and developmental diagnoses based on what is known of the family history and birth. Many of these observations are done without expert advice or training. At this point, all parental rights have been signed over to the state, and there is usually no parental interaction.

KEY WORDS:

microphthalmia, congenital anomalies, misdiagnose, conformer

All risk factors are listed on the infant's chart under the initial diagnosis. The high risks of many orphans win them a diagnosis of at least "delayed." Within a few weeks, almost all children are transferred to state-run baby houses where they reside for roughly four years.

In Russian orphanages, a treatable condition such as microphthalmia can become a terrible dilemma. Because of ignorance and misdiagnoses, children can be segregated into inappropriate classifications. Many of these children have limited individualized care. Even in the best of cases, children who are closest to normal health at birth become retarded to some degree after these four years of collective living because they are deprived of individual nurturing. An alarming number of less resilient infants seem to succumb to a self-fulfilling diagnosis of retardation.

TRAVELING TO RUSSIA

Traveling alone, I left New York City for Moscow in June 1998. Most international flights go in and out of Moscow, the capital. After the long flight, I had a day

layover before going on to a second (interior) airport on the outskirts of Moscow, where I took a six-hour flight due east to one of the largest cities in Siberia, Krasnoyarsk. This isolated city, with a population of almost one million, has only recently relaxed policies to allow Western visitors. I spoke no Russian. Thus, I was thrilled to see the smiling face of my translator, Julia, waiting for me at the airport. Julia was my only source of communication; she accompanied me throughout most of my visit.

Nearly all the logistics of my trip, including arrangements for the translators, the specific children in need and the orphanages to be visited, were coordinated by a few U.S. agencies. Many of the children with a disability were candidates to be adopted through international agencies; however, "healthy" children with no obvious disability or defect would be available first to Russian families. Infants under two years of age were always viewed as the most desirable for adoption. On the other hand, older children, especially those with a disability, face a very grave future.



I had an opportunity to visit the Krasnoyarsk Center of Eye Microsurgery and found it quite interesting. The center has numerous ophthalmologic clinics and diagnostic services, including a glass ocular prosthesis laboratory. The two technicians I met produce (hand-blown) stock glass eyes for the entire Siberian region. I was told that glass is used because of the speed involved in making these stock eyes. While the laboratory did have basic plastic supplies to produce prostheses, glass was the more comfortable medium. The stock sets that the two technicians produced would be sent later to ophthalmologists and opticians in the region to dispense. I was told that there is very limited custom work done in this particular region because of the time involved and the lack of skilled technicians to fashion acceptable prostheses.

I found the fact ironic that Russia's medical community has the facilities and capabilities to care for many of its needy children. In fact, in state-run medical care, all citizens are eligible for services, including prostheses. Only medication incurs a charge. Unfortunately, because of the frustrating economic situation and gridlock in caring for something other than basic needs, prosthetic restoration, especially for microphthalmia, is viewed as a mystery in terms of treatment. Orphans usually go untreated. While many of the bureaucratic issues seemed ridiculous, I wanted to remain as objective as possible. Besides, I was not there to judge shortcomings. Staying focused on the mission seemed to be more productive.

Several well-documented reports and presentations have been prepared on fitting and fabricating prosthetics in Third World countries. As helpful and informative as these shared experiences are, I did not bring fabrication equipment. Because of the great distance to travel and since the majority of children I would be seeing would be microphthalmic, I elected to bring only conformers and an assortment of temporary prostheses. I believed that with limited time and unfamiliar surroundings, this limited supply would be the most effective and efficient way to work with these children.

The quality of orphan care varies widely across Russia. The actual conditions of the orphanages I visited varied from dark and dingy to very neat and bright. Contrary to the Western perception, I did not see any abuse or neglect. The reality is that orphanages by their very nature are sorrowful places. The

caregivers in these facilities treated the children with firmness but with dignity. It was brought to my attention that there has been a marked improvement in the conditions of the orphanages, especially the baby houses, because of the substantial assistance from international adoption agencies.

I visited 15 orphanages during my Russian trip, most within a two-hour drive of Krasnoyarsk. I always met the director of each orphanage, all of whom seemed very organized and acted graciously toward me. The directors' personal commitment to the children's welfare was the main reason I was allowed to see and work with these particular orphans.

The children needing prosthetic intervention would be led into a designated room. I would use a pillow on the tabletop to work on the infants. The older children would sit in the extra chair. While each facility differed, there was usually a table and chair with a sink nearby to wash my hands.

The ages of the children I saw ranged from eight months to seven years (Figures 1 and 2). Ten children had microphthalmia and five others had a congenital absence of the eye. I also met one child whose congenital condition left her with a missing ear. None of the 15 children had ever been seen by an ocularist or ophthalmologist about prosthetic care. I found all of the children to be well disciplined and behaved, although somewhat scared of their particular defect and because they were getting this special attention in an unfamiliar room. With up to 400 children in each orphanage, individual attention is very rare.

From the start, my main objective was to fit each child with a clear conformer or a temporary eye, and then to instruct the director on follow-up care with an ophthalmologist, who could possibly enlarge the conformer or prosthesis. I was able to fit at least a conformer on each child, and I was surprised at how adaptable the microphthalmic eyes were to the shape I tried. In the back of my mind, I had concerns that because there was no prior treatment, some of the children would have a difficult time accepting the conformer. I had brought a portfolio of my work, showing before-and-after photographs of similar cases. I showed all of the staff the difference a prosthesis can make. I felt that if I could inspire the staff to follow up and take the child to an ophthalmologist, additional work could be done. I even took the liberty of passing out the phone number of the prosthetic



Figure 1. Two-year-old girl, microphthalmic OD – Achinsk, Russia

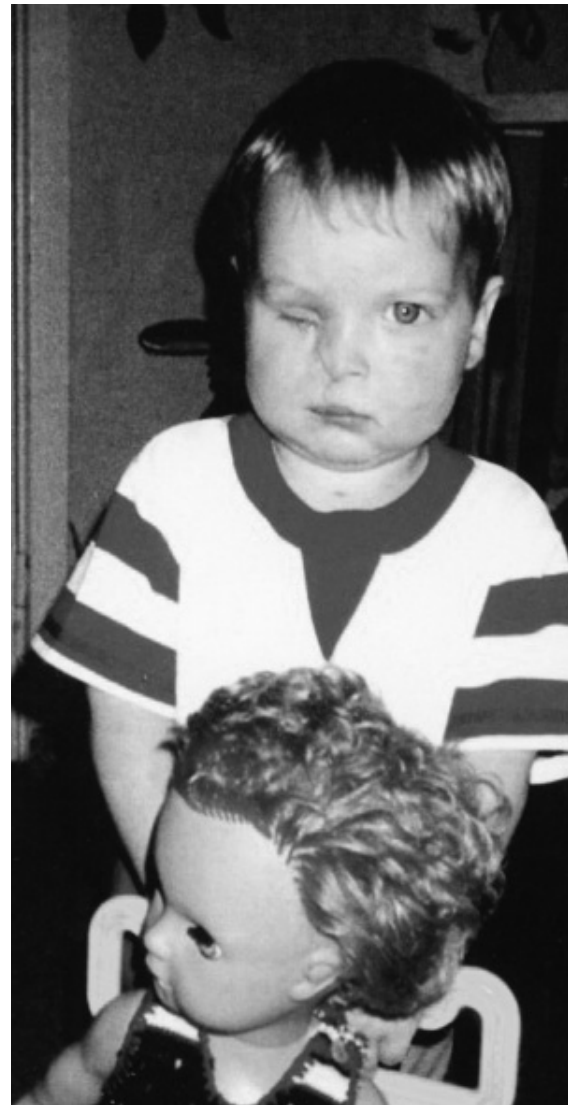


Figure 2. Three-year-old boy, microphthalmic OD – Krasnoyarsk, Russia

eye clinic to the directors I met and encouraged them to make arrangements for visits. While fitting conformers was not the most ideal treatment option, it was a start, and hopefully the beginning of long-term quality care and acceptable appearance.

CONCLUSION

We are all aware of the impact a prosthesis can have on an individual. As ocularists, we have also seen how easily microphthalmia can be treated through a series of prosthetic fittings. The situation I encountered in Siberia was not necessarily a Russian problem. It is more an economic crisis that one country is experiencing, and it shows some of the tragic casualties from such a crisis. It also reflects a social stigma that society can place on the eye and eye loss. Walter Tillman does an excellent job in describing this mystique of the eye in his book, *An Eye for an Eye*.⁴

I saw one country's extreme dilemma in dealing with unwanted children. Every country has its own problems and cruel realities of economic hardships and prejudices. Seeing children placed in orphanages because of microphthalmia (and other birth defects) was an emotional experience. To me, it brought new insight to the work ocularists perform and the impact it can have.

While it is difficult to change society's impression of the loss of an eye, as ocularists we have the ability and skills to treat these special cases. We can be placed in a position to impact a person's life, and hopefully to make a difference.

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